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The abuse, neglect and mistreatment of older people in care homes and hospitals in England: observations on the potential for secondary data analysis

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Executive Summary

Introduction

This study has investigated what sources of data exist on the subject of elder abuse in care home and hospital settings in England. It was commissioned by the Department of Health and Comic Relief. We used a broad definition of elder abuse to cover mistreatment, neglect and abuse. Some of these subjects are criminal offences; others are contrary to professional codes, service standards or breaches of human rights. Defining elder abuse is not easy, as the recent study of definitions produced for this programme of research (PANICOA) confirms (Dixon et al 2009). The main part of this study involved ‘desk research’ – an exploration of what data is collected, why, by whom and about what. In addition, a set of interviews was undertaken with people who collect and analyse information on this subject and those who make use of such information to uphold older people’s rights. We found that data are scarce and limited, definitions and collection are unsystematised centrally and locally, and currently demand collation from various and disparate sources.

This report brings together this information to:

- identify the different ways in which data on abuse of older people in hospital and care home settings are collected and collated;
- highlight areas where we can have confidence in the reliability of information;
- identify gaps in the information sources; and
- make recommendations to policy makers.

Findings

This section describes the main sources of information investigated by this research.

First, in each local authority (council) area, Adult Safeguarding Boards produce annual reports which are a valuable potential source of data on the abuse, neglect and mistreatment of vulnerable people within their locality. However, the nature and quality of the data collected and reported vary from area to area and the location of the abuse may not be recorded or difficult to deduce. In 2010 the NHS National Information Centre for Health and Social Care, set up a data collection system to draw together data on referrals to local councils about the abuse and neglect of adults, including people living in care homes or being treated in hospitals. The first results of this will be published in 2011. It is anticipated that this will be the best source of data so far on the reported abuse and neglect of older people (and other adults) in care homes or hospitals (and all other settings) in England. However, the future of this data collection system (AVA) is uncertain because changes have been proposed by government about what information it wishes local councils to collect. For example, in October 2010, the Rt Hon Eric Pickles, Secretary of State for Communities and Local Government, announced that the National Indicator Set was to be abolished (Pickles, 2010)

Other local sources of data include information from the Independent Mental Capacity Advocacy (IMCA) Services which is reported to the Department of Health. Although IMCAs may be appointed for people lacking capacity and without family or friends to advocate for them in situations of possible abuse (either in their absence or if they have been implicated in the abuse) this is a small data set when compared to the estimates of older people who may have been subjected to abuse and neglect.

Moving to data about individual services; the regulatory bodies are a potential source of data on the subject of abuse and neglect. The Care Quality Commission (CQC) produces focussed reports and reviews on regulated health and social care services and there is the possibility that a future CQC special review may generate important and sophisticated data.

In the NHS substantial data are collected from Incident Reporting systems (estimated 3.2 million incidents in total). The NHS also participates in the National Confidential Enquiry Systems. A recent Inquiry (November 2010) covering outcomes for older people receiving hospital treatment raises grave concerns about the quality of treatment and care for older people following operations. Additionally, the annual NHS Staff Survey contains information about errors, near misses and incidents, covering their handling and reporting. While this is an extensive body of information, not all of it relates to abuse or neglect and may need further refinement to extract such information.

Several professional regulatory bodies publish reports from their ‘fitness to practise’ committees. Only the Nursing and Midwifery Council (NMC) publishes data which identify the nature of the allegation or offence in sufficient detail to identify incidents of abuse and neglect, and their locations. However, even this information does not identify the age of the patients concerned and the NMC’s definitions of abuse and neglect are its own.

There is no register of social care workers, covering care assistants working in care homes, for example, and so data regarding this huge workforce and incidents of possible abuse or neglect that might be brought to the attention of public bodies are confined to situations where they have been dismissed or would have been dismissed for causing harm or risk of harm. In these circumstances, workers (including volunteers or former workers) are referred to the Independent Safeguarding Authority (ISA), which makes a decision about whether to place them on a barred list (formerly the Protection of Vulnerable Adults (POVA) List). People who are not working directly with vulnerable adults are not covered by this system. The ISA keeps records of people who have been referred because allegations of abuse have been made as well as those who have been barred from working with vulnerable adults and children in certain roles. Their records categorise the kinds of harm, the roles of perpetrator and where the incident took place (data relating to the former POVA List related to registered care settings such as care homes but not hospitals). While there is little information about the individuals who have been harmed or placed at risk of harm, other than the kinds of service they were using, these data (when relating to POVA) have been subjected to substantial and fruitful analysis (Stevens et al 2008; Hussein et al 2009).

The UK National Data Archive holds data from the small number of studies relating to the experience and treatment of patients and residents, including older people, in care homes and hospitals. The Archive also holds data on the prevalence of the abuse of older people in the community, but no studies were identified that looked at the abuse, neglect and mistreatment of older people in care homes and hospitals. There is scope for the data from the PANICOA research initiative to be submitted to this Archive.

The campaigning body Action on Elder Abuse (AEA) highlighted the need for better data in its report on ‘Adult Protection Data Monitoring’, and has generated data from its telephone helplines. Its report informed the development of the AVA system (mentioned above). Some details of the calls to AEA’s helplines have been used for secondary analysis to describe the

type of abuse reported and to provide illustrative case studies. Other campaigning groups have also provided valuable accounts of personal experiences.

Analysis of complaints and inquiries offers some insights into the prevalence and impact of elder abuse and mistreatment (for example, the Kerr-Haslam Inquiry, and the report on the Mid Staffordshire Hospital). Some of these are case studies while others take a more system wide view. A recent analysis of 22 Serious Case Reviews (SCRs) provides detail of incidents where harm or serious harm occurred to a vulnerable adult and investigations occurred (in care homes and home care but not hospitals so far) in order to inform local partnerships and practice. Overall SCRs have been little analysed, partly because their formats and thresholds are so variable, but they offer rich narrative descriptions of individual and system failures.

Conclusions

This report has identified and described the main data sources relevant to the mistreatment and neglect of older people in care home and hospital settings.

Its messages are for the consideration of policy makers; regulators, local Adult Safeguarding Boards and commissioners, the research and information communities.

Policy makers: it would be fruitful to consider the impact of the changes proposed to the AVA system – an Equalities Impact Assessment might be one route to investigating this. There is scope for national collation of prosecutions under the Mental Capacity Act 2005 and related legislation and continued monitoring of the effectiveness of the IMCA service in the area of safeguarding. National data collection around the workings of the Mental Capacity Act 2005 is an example of where central government activity is valued and useful. This debate about national data systems in this area is not only relevant to the work of the Department of Health but to the work of the Home Office and the Department of Work and Pensions, particularly around forms of financial abuse such as fraud and theft. We recommend the establishment of a Data User Group to help make the most of the large amount of data that is currently demanded of the care home and hospital sector. We further recommend that policy makers address the confusion of definitions and classifications in this area.

Regulators and professional bodies: analysis of material relating to professional fitness to practice hearings might usefully consider ages of staff and service users involved and location of offences or poor practice – the regulators may wish to consider a common data collection framework. New working arrangements with the Independent Safeguarding Authority might offer opportunities to consider this. We recommend that the Care Quality Commission pays attention to data use and the needs of wider stakeholders in preventing and responding to elder abuse in care home and hospital settings for which they are responsible as regulators.

Adult safeguarding boards: if the AVA system is not to be nationally mandated then local boards may wish to consider a minimum data set for their areas. A common framework for this would facilitate analysis and comparison and potentially be value for money. Boards may wish to consider placing the summaries of any Serious Case Reviews in the public domain and to provide information on any changes that have occurred as a result. Consistent engagement with the Department of Work and Pensions and Police services at local levels may broaden their scope to collect local data relevant to financial abuse.

Commissioners: in considering reports of Serious Untoward Incidents (SUIs) that may be referred to local safeguarding services; commissioners should have in place a system to ensure that this is carried out and be aware of providers' different definitions of SUIs and other related alerts. Changes in primary care commissioning need to resolve responsibilities for activities that are currently being undertaken by Primary Care Trusts (PCTs) and Strategic Health Authorities (SHAs). There is scope for debate in the NHS and other areas about the management of poor practice which is system related. If this does not occur there are risks that the net of 'mistreatment and neglect' will be cast too wide.

Research and information communities: should offer clarity of terminology and should archive data sets. Data concerning hospital events, such as Serious Untoward Incidents, may be worth further investigation beyond traditional patient safety parameters. Incidents and patient safety concerns may be worth further investigation to find solutions or to minimise their likelihood and harm.

Older people's groups: may offer assistance and support to individuals and families in pursuing matters, in supporting campaigning organisations and in promoting a culture of service quality rather than unwarranted blame. Their role in exposing issues in hospital settings is being newly mirrored in addressing problems in care home locations. Many of these groups are supported by staff working in social and health care services who are equally concerned about upholding the rights of older people, which, of course, includes the right not to be abused by other residents in care homes, their visitors or strangers.

Introduction

1. Introduction, Aims and Objectives, and Background

Introduction

In 2009 we were commissioned by the Department of Health (DH) with Comic Relief (under the PANICOA programme) to investigate potential data sources, suitable for secondary analysis, on the abuse, mistreatment and neglect of vulnerable older people in care homes and hospitals in England.

This research was in response to the DH call for an initial scoping exercise of existing secondary data sources. We sought to investigate ways to improve the co-ordination of data collection from different sources and the analysis of quantitative and qualitative data sets. We suspected that data would be partial, complex and multifaceted; we knew that there existed a range of data that reports ‘abuse’ and ‘crime’, a wealth of regulatory data about good and poor practice and powerful testimonies of what happens when things ‘go wrong’. We were aware that many organisations collected information of various types and some analysed data, but knew also that much data was not collated nor used to maximum effect. In the light of policy goals to remove unnecessary bureaucracy and to encourage risk taking and choice, reinforced by the Coalition Government (HM Coalition 2010), the sustainability of existing data collection mechanisms may be even more fragile. This report notes that the future of one particular set of information may be in jeopardy.

Aims and Objectives

The main aim of the study was to assist policy makers to improve the collection and analysis of existing data; to optimize their use for policy development, quality assurance and to contextualise findings from current and future data. We aimed to produce a ‘map’ of data sources, characterising their content and purpose as well as the quality of the data, and explored ways in which secondary data analysis may be fruitfully and efficiently undertaken. The study focused on elder abuse and neglect, a broad and contested subject (Dixon et al 2009). There may be scope for future investigation of associated areas such as the workings of the NHS Information Standards Management Service and in making connections to the wider information systems related to capturing, storing, and transmitting data – and indeed all information governance issues. While the focus of the study is on elder abuse, definitions of old age vary. Walby, Armstrong and Humphreys (2008) comment, in regard to data sets and equalities more generally, that while gaps in the collection of data on age are rare, some challenges remain: these include the need:

‘to ensure that the same age categories are used; to be careful not to map the distinction between retired and working onto age in too simple a way; and consistently to note when upper age limits are used in surveys’ (Walby et al 2008)

Their review of equality statistics contributed to the work of the Equality and Human Rights Commission (EHRC), which aimed to map the equalities landscape.

Our study was also commissioned both to scope existing sources of data through desk research and to consult with existing data collection groups and data users, such as policy analysts and regulators. We interviewed key stakeholders to seek their informed views and experiences and have brought these together with a series of recommendations for policy makers and other stakeholders.

Within these aims, our objectives were to:

- Explore existing incidence data of abuse and neglect, from selected crime statistics, complaints sources, regulation and inspection data, referral data, helpline data, inquiries and reviews, the Independent Safeguarding Agency (ISA, incorporating data from the Protection of Vulnerable Adults List) data, regulatory professional bodies; and to determine possible overlap and gaps, the use and benefit of such data and the ways in which such data might be more efficiently collected, stored and analysed;
- Explore ways in which local authorities regularly collect data on adult safeguarding, and other data, to see if these may be used more effectively to monitor the quality of care and to offer suggestions of where preventive work might be best targeted in care homes and other similar settings;
- Identify views about the adequacy of current data in light of the emerging personalisation agenda (which may be applying more widely to older people in care homes and in settings such as extra care or housing with care settings) and what data might usefully support this transformation and if it is possible to assure the public that the changes have not led to increased levels of harm and neglect;
- Explore the robustness of data, to see if they are fit enough for purpose to assist in the identification of abused residents/patients or in the prevention of abuse and neglect, or if accounts reveal windows of opportunity to support disclosure;
- Investigate the nature and extent of problems of 'abuse' of care-workers and other staff and residents by other residents/patients, or by visitors to care homes and hospitals, using existing information sources.

However, this is a fast moving area, thus while several developments were envisaged prior to the start of the study, such as possible changes arising from the review of the multi-agency guidance document *No Secrets* (DH 2000) and the inception of the Independent Safeguarding Authority (ISA), there have been developments in other spheres. For example, the findings of the former Disability Rights Commission (DRC) (2004) on hate crime have added to our knowledge of the extent of the problem of abuse, although most data on this subject relate to community settings. The findings of studies exploring elder abuse in the UK among people living in their own homes (O'Keefe et al 2007) are being further analysed and the methodology replicated elsewhere (Naughton et al 2010). Other developments relate to the change of government but at the time of writing (January 2011) detailed policy direction has not yet been reported in respect of the future of *No Secrets*. Further anticipated intelligence around data includes the report on Financial Abuse being undertaken by the Association of Chief Police Officers (City of London Police) which has collected new data on this subject. As we shall see, greater amounts of data about adult safeguarding referrals, investigations and outcomes will be arriving from local authorities in their current lead role in multi-agency protection and safeguarding of vulnerable adults (anticipated 2011). However, the intended cuts to national performance data collection, may in time include cutting sources of data on abuse. The new Care Quality Commission is in place but so far it has not reported on adult safeguarding or elder abuse in detail. With reference to personalisation, while the Coalition Government (DH 2010a) has announced its vision for adult social care, there is little yet from data arising from care home and hospital settings that relates to personalisation and safeguarding.

Study background

Within the context mentioned above, this study took place following a decade of rising concern about elder abuse that has prompted work on defining and clarifying the nature and scale of the problem (see Dixon et al 2009). Much of this concern relates to care home and hospital settings (Castle 2010; Patients' Association 2010a). The evaluation of the National Service Framework for Older people, *Living Well in Later Life* (Healthcare Commission, 2006), concluded that Protection of Vulnerable Adults procedures were established in most communities in England, although it found that monitoring, reporting and analysis of incidents of abuse and the outcome of investigations could be strengthened.

In addition to the varied definitions of elder abuse and neglect (summarised by Dixon et al 2009) there are other factors germane to data collection and analysis on this subject. The limited knowledge base in the area of adult safeguarding may be attributed to ageism (because it is mainly older people who are victimised or at risk) and not just deficits in information technology or analysis. Many older people are clear about the undermining effects of ageism on their daily lives, ranging from at times the patronising and thoughtless treatment from care staff, to the failure of some mainstream public services, such as some health services, to take older people's particular needs and aspirations seriously (Centre for Policy on Ageing 2009). Given its deep-rooted nature, evidenced by its continued pervasive presence despite the increasing proportion of people aged over 65 (Angus and Reeve, 2006), addressing ageism is likely to be a long-term task that requires action at a number of different levels. Adult safeguarding stakeholders may need to consider the pervasive impact of ageism as part of explanations for mistreatment and neglect but also in respect of limited data collection and data usage. For example, the International Violence Against Women Survey (IVAWS) surveyed women but only up to the age of 69 years (Mouzos and Makkai 2004) and much of the data concerning violence and sexual crime are focused on domestic and family settings thus excluding care home and hospital based populations.

The Equalities and Human Rights Commission may prompt changes of perspective through its encouragement of greater attention to age-related social exclusion and, in November 2010, it launched an inquiry into home care of older people. The Commission asserts that there are potential risks to human rights when care is provided '*behind closed doors*' in people's own homes, and that far greater attention has been paid to the human rights of older people in institutional settings such as hospital, residential and nursing care. This current research would not however be so confident that data relating to care home and hospitals are indisputably robust.

The Healthcare Commission (now the Care Quality Commission) argued that the personalised, tailored responses from public services to older citizens, as described in policy documents (e.g. Department of Work and Pensions (DWP), *Opportunity Age*, 2005), were not yet a reality for many older people and their carers (Healthcare Commission 2006). This view was supported by the Audit Commission (July 2008) that emphasized that public services have not generally devised strategic responses to their ageing populations. While some public sector organizations may be building a shared vision of services for older people through Local Area Agreements and concepts such as Total Place, the Healthcare Commission argued that sustained change would not take place unless all partner organizations shared a view of the direction in which they want to move, how they plan to get there and how they would determine progress and achievement. Furthermore, the government has decided to cease national monitoring of Local Area Agreement, (Pickles, 2010). This may remove a driver to maintain the shared vision about older people's services, particularly in the light of the cuts in

local authority budgets announced in the Comprehensive Spending Review (HM Treasury 2010). The absence of a shared strategy results in an inconsistent and uncoordinated range of services, confusion of data from monitoring and other exercises, and a focus on scandals and inquiries that often portray older people in need of ‘rescuing’ and as having limited agency.

Campaigning and academic work has also addressed these shortcomings, for example, projects have concentrated upon the collection and use of data, include: 1) the Action on Elder Abuse study of adult protection referrals (Action on Elder Abuse (AEA), 2006), 2) the work by Cambridge et al (2010) on adult protection in Medway and Kent Councils and their partners, 3) the national study (Penhale et al 2007) of local adult protection partnerships and regulation, 4) studies of advocacy; and 5) the analysis and studies of decision-making around the Protection of Vulnerable Adults (POVA) List (Stevens et al 2008).

Limited and unreliable data

It has been widely observed and indeed it is the genesis of the PANICOA research programme that data regarding abuse and neglect in care home and hospital settings are not fit for purpose. However, this is not confined to the UK. In the United States (US) Wood (2006, p8) observes:

...the panoply of “alphabet soup” databases with varying—and all too frequently, little—potential for shedding light on the incidence and prevalence of elder abuse.

As Spencer and colleagues (2008) comment in relation to Canada, data in this country are also unreliable and inadequate. For example, its formal complaints system significantly underestimates instances of abuse or neglect, since residents and families are often unwilling to make a complaint. According to the Manitoba Protection for Persons in Care Office, of 3339 complaints to their Office between 2001 and 2005, only 2.4 percent of these calls came from persons in care (that is, the residents). Spencer and colleagues (2008) suggest that Canadian government data are inadequate for many reasons. In the province of New Brunswick, for instance, while adult protection services cover abuse in community and care home settings, unlike some other adult protection provinces, there is still no means to distinguish abuse case files where residents live in care homes from cases where they live independently. In Canada, because provincial and territorial systems are highly variable, Spencer et al conclude that it is impossible to generate useful estimates of abuse and neglect in residential care. They suggest it is difficult to separate estimates of neglect from reports about problems with the quality of care:

‘These problems include high rates of psychotropic drug use, poor management of behavioural symptoms among residents with Alzheimer’s disease or other dementias, inappropriate use of physical restraints, and poorer functional outcomes (which may or may not suggest care needs being neglected)’ (Spencer et al 2008, p32).

These problems are not confined to Canada or other developed countries but are found in the literature worldwide. Despite major government investment in a very large National Nursing Home Survey (NNHS) in the US, the most recent report suggests there remains *potential* for using this survey’s findings as a resource to improve nursing home care although the survey provides an important profile of the nursing home population:

Data collected from the new items in the 2004 NNHS may be used to assess quality-of-care issues, including the need for emergent care, the presence of pressure ulcers, the number and types of medications taken, pain management... The 2004 NNHS quality-of-care measures discussed above suggest that continued efforts may be needed to reduce the number of residents who receive emergent care, develop pressure ulcers, sustain falls, or experience pain while in the care of a nursing home facility. (Jones et al 2009)

In the UK there is no similar sample profile of care home residents to guide such decision making. Moreover, even if there were such data, commissioners may not be easily able to use such these data in practice. Berlowitz and colleagues (2005), for example, report that nursing homes that are performing well on one quality measure may be performing poorly on another and *vice versa*, so it is difficult to consistently identify which may be the best or worst.

A decade ago, from the perspective of local adult protection in an English local authority, Quigley (2001) observed:

‘The characteristics and causes of adult abuse are under-researched, so the opportunity to make recommendations for practice has been limited. Action to prevent or minimise abuse in care settings has to be informed by a reasoned view of causation if it is to be effective’.

It is with this in mind that this report is written, data are not an end in themselves but an opportunity to prevent adult abuse and to enhance the rights of older people. Importantly, researching elder abuse in hospital and care home settings needs not to be seen as an exercise in blame. There is emerging debate that because health and social care staff are at increased risk of both bullying and violence when compared to staff from other industries and that this too may affect quality of care as we describe in the final part of this report. Woodrow and Guest (2008) suggest ‘*it is possible that bullying and patient violence in healthcare may be linked in some way to detrimental outcomes not only for staff, but also for patients. This link has been largely ignored in the literature thus far*’.

2. Methods

The purpose of the desk based part of this study was both to identify potential data sources and also assess their suitability for secondary analysis. A multi-phased search strategy was adopted looking at:

- Councils with Adult Social Services Responsibilities (CASSRs) and the data collected by Safeguarding Boards (Adult Protection Committees) within those CASSRs.
- Institutional and professional regulatory authorities and complaints handling bodies such as the Care Quality Commission (CQC), the Council for Health Regulatory Excellence (CHRE), the Nursing and Midwifery Council (NMC) the Independent Safeguarding Authority (ISA) and the Parliamentary and Health Service Ombudsman.
- Bodies with responsibility to collect and or publish data such as the National Health Service Information Centre for Health and Social Care (covering the NHS and local councils) and the Economic and Social Data Service (ESDS) UK Data Archive.
- Independent charities operating in this field such as Action on Elder Abuse, Dignity in Care, and the Clinic for Boundaries Studies (formerly Witness and the Prevention of Professional Abuse Network - POPAN).
- A scan of recent research in England and Wales, and of articles in the *Journal of Adult Protection* and searches of internet search engines and Ageinfo to identify potential data sources identified by researchers and used within academic articles.

The current study is a good indicator of the data (or lack of data) available on the abuse, neglect and mistreatment of older people in care homes and hospitals but it is not exhaustive or comprehensive. Data themselves may not be useful or meaningful, so this study investigated data relevance and judgements through interviews with key informants as described in the following section.

Interviews were undertaken with 16 key informants (see Box 1) during summer 2010. In one interview with members of the Care Quality Commission (CQC), which had to be conducted as a teleconference, three officers of the CQC participated. This was a time of some uncertainty in some of the organisations contacted and participants were assured of anonymity. Thus there are no details in this report of the age, gender, professional qualification or precise job titles of those participating. Based on an initial search of the literature and the aims of the study, a broad interview schedule was developed to meet the highly varied roles and experiences of participants. Interviews were undertaken face to face at a place (with the CQC exception) and time convenient to participants or by telephone if this was not possible. Their views were audio-recorded with permission. In light of the semi-structured nature of the interview schedule, analysis was undertaken by theme and verbatim quotations are used in this report to illustrate participants' understanding and use of the data sets identified.

The semi-structured interview schedule concentrated on the following questions:

In terms of recognising and preventing abuse (neglect, infringements of dignity etc) of older people in institutional settings (e.g. hospitals, care homes):

What data do you/your organisation collect and hold?

What are the data based on?

What data are you/they NOT collecting?

How do you/they collect data? Data format and storage?

How do you/they make judgements about what data are needed?

How are the data used?

Why are these data collected?

What are you/they required to collect?

When are data collected?

Are there critical points or time periods?

Who/What Determines what data are collected?

Who collects the data, processes data, analyses the data?

Trends

Are you/they measuring trends?

What trends?

Complaints:

How do you/people in your organisation classify complaints?

How do you/they collect data about complaints?

How do you/they deal with complaints, e.g. re lack of dignity, poor practice?

Clinical governance

What do you/they use to make a decision about clinical governance?

Ultimately

Are the data collected useful?

What would be useful?

How could data collection change so that it can ultimately be used more effectively to identify and prevent abuse etc of older people in institutional settings?

Box 1: Interview participants (anonymised) (16 participants in 14 interviews)

01	Advisor, Department of Health.
02	Nurse Consultant Older People and Clinical Lead Dementia, NHS Foundation Trust
03	Adult Safeguarding Lead, County Council
04	Safeguarding consultant, DH
05	National Clinical Assessment Service, (part of the National Patient Safety Authority, NPSA)
06	National Reporting and Learning Service, (part of the NPSA)
07	National Reporting and Learning Service, (part of the NPSA)
08	Quality Contracts Manager, Quality Team, Primary Care Trust (PCT), NHS
09	Patient Incident Officer/ Patient Safety Manager, PCT
10	Safeguarding Vulnerable Adults Co-ordinator,
11	Nursing Advisor, DH
12	Director of Policy and Communications, National Care Organisation
13	Safeguarding consultant, report developer, analyst. Care Quality Commission (CQC) (three participants)
14	A Lead Officer, Nursing and Midwifery Council

Participants were keen to point out that this was a fast changing area and that data collection processes reflected this. Speaking from a background of NHS hospital management, one participant observed:

‘Next week is the first new safeguarding committee at the hospital, adult and children, for the first time. Safeguarding has always been overshadowed by the fact that we are a children’s hospital (by tradition). Safeguarding for children has always been big on the agenda. Next week we have a new committee being formed for adults and children. We will start to bring together parts of the data. There will be restructuring.’ (Nurse consultant older people, 2).

Apparent in all the interviews was that the whole area of adult safeguarding continues to evolve. All participants reported that services and systems were frequently changing, including those influencing data collection, storage and usage. Many also described how their own services and roles were in flux. Despite some feelings that the DH consultation on *No Secrets* (DH 2009) was placing ‘on hold’ some decision making and developments, the subject of safeguarding was caught up in other organisational changes.

Findings

3. National and local health and social care data collections

This chapter describes nationally collected data on abuse and neglect occurring in care home and NHS in patient settings. It includes data collection specifically intended to capture information about abuse and neglect as well as general data collection, which includes the topic.

The NHS National Information Centre for Health and Social Care

In 2006, in its report *Adult Protection Data Monitoring*, Action on Elder Abuse called for the national collection of data on Protection of Vulnerable Adult referrals (Action on Elder Abuse 2006). Possibly the richest potential source of data on vulnerable older people in care homes and hospitals in England will be the emerging data set being collected from all Councils with Adult Social Services Responsibilities (CASSRs) by the NHS National Information Centre in Leeds. In 2007 Matt Cuff and Kate Anderson at the NHS Information Centre in Leeds developed a pilot data collection project to collect data on the **Abuse of Vulnerable Adults (AVA)**.

Following the pilot project in 2007, a report was made to the development group. Various definitions were revised and the data collection tool was published on the web in early 2010. At the time of writing, all CASSRs have now made their returns and the results are expected to be published in 2011.

The data return spreadsheets from the pilot study were split by CASSR and contained no data. It is not clear whether the published data will only be by CASSR or will also be aggregated nor, if not, how easy it would be to aggregate and analyse the data.

The data collection tables follow in detail. These show that potentially, from this data, it will be possible to isolate information about referrals concerning abuse and neglect in care homes and hospitals and perform secondary analyses. In light of the current policy interest in *dementia care*, for example, analysis of data relating to this group by location may be facilitated. Item 8b will identify the national incidence of referrals to councils for Serious Case Reviews for the first time. However, it is important to recall that a referral and an investigation do not necessarily mean that there has been abuse or neglect. There are false positives in this area and they too may lead to harm and distress (see Rees and Manthorpe 2010), or, as High Court cases established in respect of the vetting and barring list (POVA) allegations, this may run the risk of unfair treatment of practitioners.

The web link for the data source is

<http://www.ic.nhs.uk/services/social-care/social-care-collections/vulnerable-abuse>

The current data collection exercise covers the period October 2009 to March 2010 and was set to be repeated next year for the period April 2010 to March 2011. Importantly, the collection in 2010-11 was made mandatory. Blank tables showing how the data is collected are given in the Appendix to this report. The following data is provided, broken down by age group (18-64, 65-74, 75-84, 85 and over). Of people aged under 65, needs are broken down by:

- Physical disability, frailty and sensory impairment (Total)
 - Of Which: Sensory Impairment

- Mental Health Needs (Total)
 - Of which: Dementia
- Learning Disability
- Substance misuse
- Other Vulnerable People

The following data is collected

- Table 1: Number of alerts, referrals, repeat referrals and completed referrals by age, primary client group and gender of alleged victim
- Table 2: Number of alerts, referrals, repeat referrals and completed referrals by ethnicity and age of alleged victim
- Table 3: Number of Referrals by source of referral by age and primary client group of alleged victim
- Table 4a: Number of referrals by nature of alleged abuse, age and gender of alleged victim
- Table 4b: Number of referrals by nature of alleged abuse, primary client group and age of alleged victim
- Table 5: Number of referrals by location alleged abuse took place by type of service
- Table 6a: Number of referrals by relationship of alleged perpetrator by age and gender of vulnerable adult
- Table 6b: Number of referrals by relationship of alleged perpetrator by primary client type and age of vulnerable adult
- Table 7a: Number of completed referrals by case conclusion, primary client group and age
- Table 8a: Outcome of completed referral - Victim*
- Table 8b: Number of Completed Referrals Leading to Serious Case Review
- Table 8c: Acceptance of Protection Plan
- Table 9: Outcome of completed referral - *Alleged Perpetrator/Organisation/Service

Other data from the National Information Centre for Health and Social Care

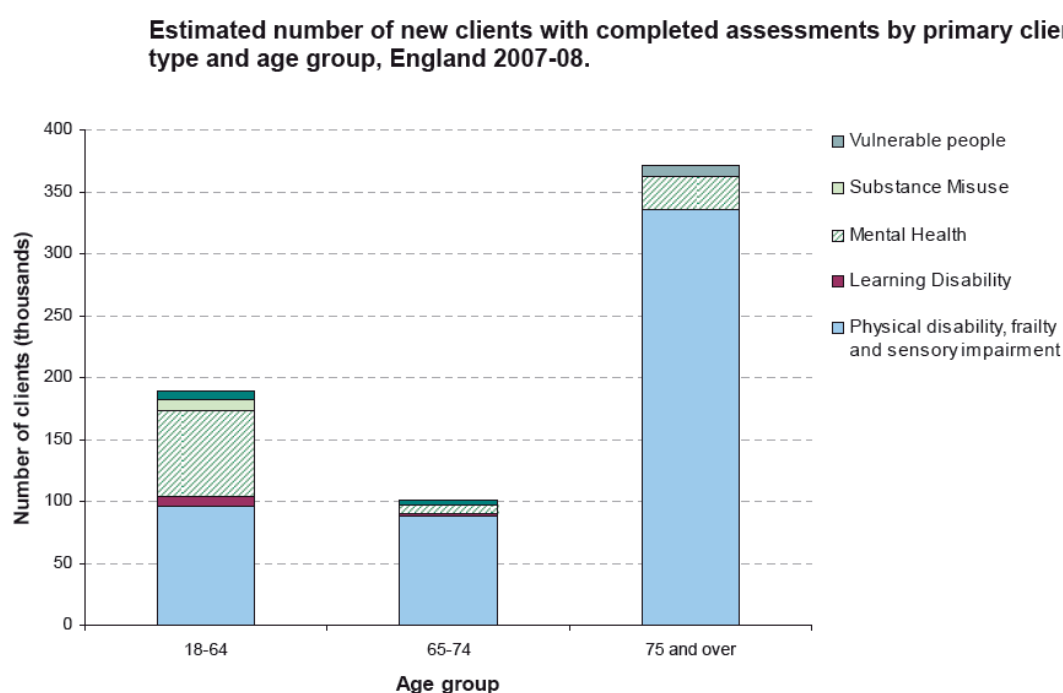
A further value of the AVA is that these data will be able to be placed in the context of other data collected by the NHS Information Centre on Referrals, Assessments and Packages of Care for Adults / Social Services Activity reports. The NHS National Information Centre currently handles production of the Referrals Assessments and Packages (RAP) of Care reports. The RAP reports are soon to be replaced by broader Social Service Activity reports.

The RAP reports give a very broad overview of referrals and assessments including a 'vulnerable people' category and the age of the client or service user. It is not entirely clear to whom the term 'vulnerable people' refers; very probably it does not simply mean those vulnerable adults who have been referred to a safeguarding service. However, data from the RAP reports are helpful in setting out details of people whom it is all too easy to categorise as 'elderly'. Such detail enables some breakdown also by age bands, as shown below.

According to the NHS National Information Centre Referrals, Assessments and Packages of Care for Adults, England (RAP1) for 2007-8:

“In 2007-08, of the 661,000 new clients with completed first assessments, about 79 per cent were classified as having a 'physical disability, frailty and sensory impairment', a further 16 per cent of clients were classified as having the primary

client type ‘mental health’, 3 per cent as ‘vulnerable people’, 1 per cent as ‘learning disability’ and 1 per cent as “substance misuse”. These proportions have remained fairly stable since 2004-05.”



Source: RAP proforma A1

The RAP reports give an overall picture of referrals to CASSRs, including the length of time to process and the overall age distribution for adult referrals (by age band).

The RAP reports are being replaced by Social Services Activity, England reports, publication of the first of which, in 2010, has been delayed. These data will merit exploration and may be a useful starting point for considering trends in ‘evictions’ from care homes, for example, since some residents have new rights under human rights extensions through the Health and Social Care Act 2008. Under this a care home is seen as performing functions of a public nature - in the case of residents placed in the home by a local authority under ss.21 and 26 of the National Assistance Act 1948. Nonetheless, the lack of a minimum data set covering care home residents in the UK restricts our detailed knowledge about this group (in contrast to the United States (US) where such a data set exists, see Jones et al (2009) on the National Nursing Home Survey).

The National Adult Social Care Intelligence Service (NASCIS)

The Referrals, Assessments and Packages of Care (RAP), Adult Social Care Combined Activity Return (ASC-CAR) outlined above, together with Personal Social Services Expenditure (PSSEX) and National Indicator Set (NIS) data and other data and tools were gathered together by NHS National Information Centre for Health and Social Care, to form a collection called the National Adult Social Care Intelligence Service (NASCIS). However, the system of performance data collection and reporting to central government is, at time of writing, in flux. As noted, the Secretary of State for Communities and Local Government, the Right Honourable Fred Pickles announced, in October 2010, that the NIS is to be scrapped, along with various other aspects of the previous performance target systems, including Local

Area Agreements, which include sets of local targets to be met by different public sector service, including local authorities and Primary Care Trusts. The NIS is going to be replaced by:

‘a single comprehensive list of all the data we expect local government to provide to central government. My aim is to make the data requirements we placed on local government transparent and to review and reduce this for April 2011’. (Secretary of State for Communities and Local Government, letter to council leaders and local authority chief executives, October 2010: p1).

It is not clear whether the Abuse of Vulnerable Adults (AVA) data collection (see above) will also form part of this package.

Local Authority data – local studies

There is a variety of reports of local data but the most well developed assembly of local data from adult protection/safeguarding services that has been collected and analysed is from the neighbouring local authorities of Kent and Medway. Based at the University of Kent, the Tizard Centre (Cambridge et al 2006) work, for example, reports that abuse type is related to location. In residential care only 7 percent of abuse reported was financial, whereas in people’s own homes financial abuse and exploitation made up 25 percent of reported cases. In addition, financial abuse is more likely to be carried out by men at home and women in residential care settings (unsurprisingly in view of the staff profile). Again, not surprisingly, financial abuse at home is more likely to be undertaken by family members whereas in care homes it is more likely to be committed by staff. This study found that 8.5 percent of adult protection alerts concerned residential/ nursing home staff, 4.7 percent concerned a manager or home owner and 15.3 percent concerned staff whose role was not known (Cambridge et al 2006).

Overall, not only are there variations in local reporting, with the local authorities of Kent and Medway being very much the exception in doing this consistently and conscientiously, the data that are often collected or reported comprise alerts or referrals. The DH (2009) in its consultation document on the review of *No Secrets*, draws attention to the lack of information about outcome measures. This again makes secondary or even primary data difficult to collect in terms of its most important feature; what happened to the person involved? The DH (2008) notes that local annual safeguarding reports do not systematically collect or analyze quantifiable outcomes for cases but cites a number of possible measures that might be employed:

- ‘There are criminal outcomes: i.e. a small number of successful prosecutions for physical assault and sexual abuse, for fraud and for theft.
- There are employment outcomes: where unsuitable workers are placed on the Independent Safeguarding Authority (ISA) Barred List (formerly the POVA) list (see above), which imposes a social care workforce ban.
- There are improved care practice outcomes: where institutionalised practices introduced for the convenience of staff have been stopped.
- There are improved care outcomes even after a death: for example, we heard that deaths as a result of medication errors in a care home were investigated by the police murder team – with valuable lessons learnt.

- There are ‘new assessments/new services’ outcomes: for example, where a carer is not coping.
- There are financial outcomes: where service users’ money is protected by the appointment of deputies by the Court of Protection.
- There are increased physical safety outcomes: either by controlling access to an alleged abuser, or by the removal of a person from a property or service setting.
- There are a small number of prosecutions for institutional negligence/neglect, for example through the use of health and safety legislation.
- There are some ‘unwilling to cooperate’ outcomes, where for example people with alleged chaotic homes/lives, which may be deemed unsafe, do not wish to change their lifestyle.
- There are ‘feeding into service planning/commissioning’ outcomes.
- There are regulatory outcomes, such as cancelling the registration of a service or manager.
- Would more clarity about the intended outcomes help to raise the profile of safeguarding adults work, and lead to greater priority and resources being dedicated to it?’ (p19)

There does not appear to have been any systematic analysis of the work of local authority Overview and Scrutiny Committees (OSCs) in respect of safeguarding. These are expected, as a minimum, to review their area’s Adult Safeguarding Board report, together with performance data from CQC inspection reports and any peer review conducted. The IDeA (now Local Government Improvement and Development (LGID): Williams 2010) notes that OSCs have legal power to require information from the NHS and to ask it to answer questions. It is not clear how far this process undertakes analyses and management of data relating to care home and hospital care and treatment or incidents giving rise to concern.

However, some information from peer reviews of adult safeguarding by LGID directly relates to the need to consider data management and purposes. All areas are said to be experiencing rises in referral rates. Humphries (2010), collating the findings of four early reviews, observes:

‘Lack of accurate and appropriate data makes it difficult for councils to judge how well they are doing in safeguarding. Development of systems in this area is a major priority. Driven by a clear and shared understanding of what they are trying to achieve, this should include agreed local indicators of performance, case recording systems that are outcome-based, and information systems that can generate quick and timely information on performance to frontline teams as well as senior managers’ (Humphries 2010, p10).

Safeguarding Adults Boards – Annual Reports

The 152 individual Councils with Adult Social Service Responsibility (CASSRs) have established multi-agency Safeguarding Adults Boards, replacing (by name perhaps alone) the earlier Adult Protection Committees. These Boards bring together representatives from the local authority, NHS, police, and other local stakeholders (see Penhale et al 2007). Boards are locally constituted without a ring-fenced funding allocation and it is reported that attendance by individual agencies can be ‘patchy’ (Perkins et al 2007).

Individual authorities or Boards generally produce a Safeguarding Adults Annual Report.

This report can be rich in data on abuse and neglect of vulnerable adults for the particular local authority area to which the report applies. However, the data collected and reported varies from area to area. In an article in the *Journal of Adult Protection*, considering the change in nomenclature and perhaps ethos, from adult protection to safeguarding adults, Reece (2010) gives advice on the local collection of data:

‘When using safeguarding data to analyse for patterns and trends, and to take action to mitigate emerging risk factors, it is necessary to consider:

- whether underreporting from any particular team or service may suggest a training or awareness deficit;
- whether underreporting from any particular group of users or section of the population may suggest a deficit in appropriate information;
- whether patterns in data validity checks may evidence the need for improvement in practice or oversight; and
- whether data may be able to evidence appropriate decision-making and the appropriate application of thresholds.

He continues: *‘As with any strategy, it is important to understand from the outset how to determine whether or not the strategy has been effective, so a thorough upfront examination of how you intend to measure the success of a prevention agenda is recommended. There is no ‘magic spell’ that can prevent abuse. In the same way that safeguarding adults procedures can be seen as codifying good multi-agency practice and collaborative working, it is likely that a prevention of abuse agenda will codify good practice in service provision, both within and beyond health and social care’* (Reece, 2010). Data from individual CASSRs are being brought together by the NHS National Information Centre’s AVA data collection exercise as outlined above.

Action on Elder Abuse (AEA) Adult Protection Data Monitoring and Reporting

As noted, between 2004 and 2006, the campaigning group Action on Elder Abuse carried out a project, funded by Department of Health Section 64 money, to explore current systems and make recommendations on *Adult Protection Data Monitoring and Reporting* (AEA 2006). The first part of the project requested data on adult protection referrals from all local authorities in England. This survey provided data on 15,089 adult protection referrals. Of these, 9,939 (65%) could be attributed to a particular ‘service’ group.

Older People	Learning Disability	Mental Health	Physical Disability	Sensory Impairment	Substance Misuse
29.39%	20.19%	7.29%	7.19%	0.28%	1.50%

Physical abuse was the most common form of abuse followed by financial abuse. The home was the most common place of abuse. Residential and nursing home care was the second most common place of abuse with abuse occurring disproportionately to the number of care home residents. The most common type of abuser reported was a care worker followed by a family member. Some perpetrators were themselves vulnerable adults. The most common

source of referral was social services and/or staff, followed by family members and friends. Only 19 percent of local authorities recorded the outcome for the vulnerable adult.

A more detailed pilot study of 639 referrals from 9 local authorities that volunteered to take part in the project found that in 31.8 percent of cases the abuse took place in the vulnerable adult's own home and 29.4 percent in residential care. These data were highly influential in encouraging national approaches to data collection, such as the AVA mentioned above.

AEA Helplines

Action on Elder Abuse operates the UK and Ireland's only national, freephone helpline for anyone concerned in any way about the abuse of older people. It provides information on the nature of elder abuse and indicates what action might be taken in response to abuse or to prevent it.

In addition, AEA operates a freephone helpline for one private provider of social care services, mainly care homes, Southern Cross Healthcare. This helpline is available on a telephone number publicised within each Southern Cross care home, and is available to staff, residents, relatives and friends. AEA is also piloting an Adult Abuse helpline within Essex, which provides advice and information to any adult who may be at risk of or experiencing abuse, together with a helpline email service for advocates.

These helplines are potentially a source of data on the abuse, neglect and mistreatment of older people and while they cannot provide absolute prevalence levels in care homes and hospitals, they may indicate the relative frequency of different types of abuse, the nature of the relationships between those involved, and the location of the abuse (if recorded). For example, in 2007, AEA published a briefing paper *The Cost of living: 'growing up is free, growing old is expensive'* (AEA 2007) which provided an analysis of calls to the national helpline during 2006, focussing on financial abuse. Importantly, Harding (2004) also reports personal experiences in another similar overview of individual accounts '*Hidden Voices: Older people's experience of abuse*'.

Data sets from the National Data Archive - Economic and Social Data Service (ESDS)

A number of studies lodged at the National Data Archive relate to abuse and neglect or to hospital and care home provision but not the two in combination. This Archive is an important depository nonetheless, containing, for example, the NHS Staff Survey and the NHS Adult Inpatient Survey (see below).

National Health Service (NHS) National Staff Survey

The National Health Service (NHS) National Staff Survey is carried out annually and data are lodged in the National Data Archive for surveys from 2003, 2004, 2005, 2006 and 2007. The Survey is now run by the CQC (formerly it was run by the Healthcare Commission).

The survey does not directly contain questions on abuse and neglect but provides information about the prevalence of health care incidents (under the heading 'errors and incidents witnessed') in primary, acute and mental health care and how these incidents are reported and treated. The survey also includes questions about bullying and violence, which makes it a potential source of data about 'abuse' of staff or harm caused by service users and relatives.

To the best of our knowledge the interaction of this with adult safeguarding data has not been explored although Lynne Phair has recently (2010) undertaken work in a set of NHS Trusts to consider the ways in which local incidents may have been interpreted as matters related to adult safeguarding (Phair, 2010, personal communication).

Details of the 2007 survey are:

Title:

National Health Service National Staff Survey, 2007
(NHS National Staff Survey, 2007)

Subject Categories:

General - Employment and labour
Health services and medical care - Health
Use and provision of specific social services - Social welfare policy and systems

Depositor(s):

Healthcare Commission (now CQC)

Principal Investigator(s):

Healthcare Commission
Aston University. Aston Business School

Sponsor(s):

Healthcare Commission

Abstract:

The Commission for Health Improvement (CHI) (formerly the Healthcare Commission (HC) now CQC), in conjunction with the Department of Health (DH), appointed Aston University to develop and pilot a new national National Health Service (NHS) staff survey, commencing in 2003, and to establish an advice centre and web site to support that process. Researchers at Aston University were responsible for the initial development of the survey questionnaire instrument, and for the setting up of the NHS National Staff Survey Advice Centre.

All organisations concerned worked in partnership to consult widely with NHS staff about the content of the new national survey. The work was conducted under the guidance of a stakeholder group, which contained representatives from the staff side, HC, DH, human resources directors, Strategic Health Authorities and the NHS workforce.

The purpose of the new annual NHS staff survey is to collect staff views about working in their local NHS trust. The new survey has been designed to replace trusts' own annual staff surveys, the DH '10 core questions', and the HC 'Clinical Governance Review' staff surveys. It is intended that this one new annual survey will cover the needs of HC (CQC), DH and Trusts. Thus, it will provide information for deriving national performance measures (including star ratings) and to help the NHS, at national and local level, work towards the 'Improving Working Lives' standard. The design also incorporates questions relating to the 'Positively Diverse Programme'.

Trusts will be able to use the findings to identify how their policies are working in practice. The survey will enable organisations, for the first time, to benchmark themselves against other similar NHS organisations and the NHS as a whole, on a range of measures of staff satisfaction and opinion. It became obligatory for all NHS trusts and primary care trusts (PCTs) in England to implement this new survey with a sample of their staff at the end of October 2003.

The collection of data (i.e. the survey fieldwork) is conducted by a number of independent survey contractors. The individual contractors are appointed directly by each NHS Trust in England. The contractors are required to follow a set of detailed guidance notes supplied by the Advice Centre (see web site link above), which covers the methodology required for the survey. For example, this includes details on how to draw the random sample, the requirements for printing of questionnaires, letters to be sent to respondents, data entry and submission. At the end of the fieldwork, the data are then sent to the Advice Centre. From the data submitted, each participating NHS trust in England receives a benchmarked 'Feedback Report' from the Advice Centre, which also produces (on behalf of HC) a series of detailed spreadsheets which report details of each question covered in the survey for each participating trust in England, and also a 'Key Findings' summary report covering the survey findings at national level.

The 2007 survey introduced different versions of the core questionnaire for each of the four main sectors (acute, ambulance, mental health and primary care). The majority of the content is the same across the different versions of the core questionnaire but, in addition, now includes a number of sector specific questions.

Main Topics:

Topics covered in the survey include: work-life balance; appraisal; training, learning and development; team working; health and safety; **errors and incidents witnessed**; job characteristics and arrangements; management and supervision; perceptions of organisation worked for; harassment, **bullying and violence**; and respondents' demographic characteristics (our emphasis).

Sector-specific questions include: (acute) - infection control; (ambulance) - communication and distance between trust headquarters and ambulance stations; safe working environment; (mental health) - mental health specific training; partnership working.

Coverage:

Dates of Fieldwork: October 2007-December 2007

Country: England

Spatial Units: No spatial unit

Observation Units: Individuals

Kind of Data: Numeric data; Individual (micro) level

Universe Sampled:

Location of Units of Observation: National

Population: Staff at the 572 NHS trusts in England.

Methodology:

Time Dimensions: Repeated cross-sectional study

Sampling Procedures: Quota sample

See documentation for further details.

Number of Units: 155,922 cases

Method of Data Collection: Postal survey; Self-completion

Weighting: No weighting used.

Access:

Access Conditions: The depositor has specified that registration is required and standard conditions of use apply. The depositor may be informed about usage.

Availability: ESDS Access and Preservation, UK Data Archive

Contact: Help desk: help@esds.ac.uk

Date of Release:

First Edition: 2 November 2009

Copyright:

Copyright Healthcare Commission/CQC

National Health Service National Staff Survey, 2007 – abstract from questionnaire

26. In the last month have you seen any errors, near misses, or incidents that could have hurt patients / service users?

1 ☐ Yes 2 ☐ No

If YES, please answer parts b and c below; if NO, go to Question 27

b. The last time you saw an error, near miss or incident that could have hurt patients / service users, did you or a colleague report it?

1 ☐ Yes, I reported it 2 ☐ Yes, a colleague reported it 3 ☐ No 4 ☐ Don't know

c. Please indicate the reason for the last error, near miss or incident you saw that could have hurt patients / service users. *Please tick all that apply.*

1 ☐ Clinical assessment / treatment given (e.g. incorrect application of guidelines / protocol, incorrect prescribing / dispensing / administration of medication, diagnostic error, problems with tests, scans, misinterpreting results etc.)

2 ☐ Medical equipment (e.g. medical equipment not available when needed, faulty equipment etc.)

3 ☐ Staffing levels (e.g. not enough staff, staff without adequate training to perform procedures etc.)

4 ☐ Communication (e.g. poor communication between clinical teams, or with the patient / service user etc.)

5 ☐ Problem with the admission, transfer, or discharge of patient / service user

6 ☐ Other reason(s) (please specify)

27. To what extent do you agree or disagree with the following?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
a. My Trust treats staff who are involved in an error, near miss or incident fairly.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b. My Trust encourages us to report errors, near misses or incidents.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c. My Trust treats reports of errors, near misses or incidents confidentially.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d. My Trust blames or punishes people who are involved in errors, near misses or incidents.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
e. When errors, near misses or incidents are reported, my Trust takes action to ensure that they do not happen again.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
f. We are informed about errors, near misses and incidents that happen in the Trust.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
g. We are given feedback about changes made in response to reported errors, near misses and incidents.	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

NHS Adult Inpatient Survey

The NHS Adult Inpatient Survey, while again not directly addressing the incidence of abuse or neglect in hospital care, provides insight into patients' own views of their hospital care and treatment. The age group variable allows comparison of perceptions of the care and treatment of older and younger patients.

Title:

Acute Trusts: Adult Inpatients Survey, 2009
(NHS Patient Survey Programme)

Subject Categories:

Health services and medical care - Health

Depositor(s):

Care Quality Commission

Principal Investigator(s):

Picker Institute Europe
Care Quality Commission

Data Collector(s):

Picker Institute Europe

Sponsor(s):

National Health Service
Care Quality Commission

Other Acknowledgements:

Additional funding is provided for the surveys by National Health Service (NHS) trusts throughout England. While some trusts hire an approved survey contractor, others conduct the surveys 'in-house'. Thirteen organisations have been approved by the Care Quality Commission to carry out local NHS trust surveys.

Abstract:

The National Health Service (NHS) programme of patient surveys began in 2003, and was conducted by the Commission for Health Improvement (CHI), along with the Commission for Healthcare Audit and Inspection (CHAI). Administration of the programme was taken over by the Healthcare Commission in time for the 2004 series. On the 1st April 2009, the Care Quality Commission was formed which replaced the Healthcare Commission (users should note that some of the surveys in the series conducted prior to this date will still be attributed to the Healthcare Commission).

The surveys focus on **patients' experiences in Primary Care Trusts (PCTs), and in outpatient and accident and emergency departments in Acute Trusts.**

Understanding what people think about the care and treatment they receive is crucial to improving the quality of care being delivered by healthcare organisations.

The NHS series is one of the largest patient survey programmes in the world. It provides an opportunity to monitor experiences of health care and is an important part of the Care Quality Commission's annual 'health check' of NHS patient services. The surveys cover issues that affect the quality of care that patients receive and have been identified by patients as important to them. The programme aims to:

- provide feedback from patients to health care organisations, which can be used locally for quality improvement
- gather information about the experiences of people using services to inform performance assessments and Care Quality Commission inspections and reviews, at a local level
- assess the performance of health care providers and monitor the experience of patients at a national level
- allow health care organisations to compare their results so that best practice can be shared

Further information is on the Care Quality Commission web pages.

The **Adult Inpatients Survey, 2009** was designed to provide actionable feedback to each participating NHS trust on patients' views of the care they had received as inpatients, as well as providing the Care Quality Commission with patient-focused indicators to feed into the 2008-2009 annual performance ratings check for acute and specialist NHS trusts.

Main Topics:

The survey covered issues that affect the quality of care that patients receive and were identified by patients as important to them.

Topics covered included: admission to hospital, the hospital and ward, relationships with healthcare professionals, care and treatment, pain, operations and procedures, discharge.

Coverage:

Time Period Covered: June 2009-August 2009 (annual repeats)

Dates of Fieldwork: October 2009-January 2010

Country: England

Spatial Units: Strategic Health Authorities (SHAs); Primary Care Trusts/Care Trusts

Observation Units: Individuals

Kind of Data: Numeric data; Alpha/numeric data; Individual (micro) level

Universe Sampled:

Location of Units of Observation: National

Population: Adults in England who had at least one overnight stay in hospital, were discharged between June and August 2009, and were not maternity or psychiatry patients.

Methodology:

Time Dimensions: Repeated cross-sectional study

Part of a wider NHS patient survey programme.

Sampling Procedures: Simple random sample

Each of the participating trusts drew a random sample of 850 patients from a list of eligible patients. The trusts were responsible for ensuring that their survey was carried out following the standard sampling and survey procedures, as set out in the guidance issued to them.

Number of Units: Target: 137,360. Obtained: 69,348.

Method of Data Collection: Postal survey

Weighting: Weighting used. See documentation for details.

Access:

Access Conditions: The depositor has specified that registration is required and standard conditions of use apply. The depositor may be informed about usage.

Availability: ESDS Access and Preservation, UK Data Archive

Contact: Help desk: help@esds.ac.uk

To preserve respondent confidentiality, several variables within the *National Health Service Patient Survey Programme* datasets are routinely either removed or recoded before deposit at the UK Data Archive. These include variables covering **age** and ethnicity, and data for trusts where case numbers are very small. Should users require analysis by ethnicity or access to removed data, they should contact Picker.

Date of Release:

First Edition: 1 July 2010

In respect of this data collection and others within the NHS, the interview participants discussed which categorisations and data collection methods suit different parts of the NHS. For example, a Quality Contracts Manager at the PCT said:

‘Getting the information is difficult because that’s collected within the Trusts in the ways that most suit their purposes which isn’t always what suits ours. We would want to assure ourselves that the quality of care in the organisation is good and we have a series of indicators. MRSA, C.Diff, Nursing Metrics, pressure ulcer incidence, falls, and all falls, not just the ones resulting in major harm, skin assessments, and drug administration errors. We also address these issues at regular meetings and lists of incidents that might be related to abuse. But the Trusts were reluctant to share this information. **It’s developing the sharing culture of incidents together is a problem.** We look to see if the trajectory is increasing. (We have) monthly meetings with the Director of Nursing in the PCT and meeting with the Director of Nursing at the Trust. We seek to address areas of concern but it’s not very detailed – we’re starting to gain information and we’re looking at reports and risk. They (acute trusts) report through clinical incidents and we are trying to get access to clinical governance minutes to get a clear picture. Every month there are patient safety and patient experience reports.’ (8, our emphasis).

Moves to reorganise by setting up GP consortia to replace Primary Care Trusts (PCTs) may invert the present power relationships between NHS managers and clinical practitioners described above (DH 2010b). GP consortia will put clinicians in the leading roles and may use the expertise of redundant PCT staff (such as participants 1, 8 and 9) to manage the consortia. At local levels, the traditional hospital boundaries may become more porous and see the creation of more integrated services. Hospital Trusts, NHS or Foundation Trusts, for

example, may take on community services, from nursing to social care. Both NICE (in perhaps a new format) and the Care Quality Commission – will generate standards for integrated services that will have to be adhered to if contracts are to be sustained and renewed.

Inpatient surveys may also touch upon areas that concern dignity. For some clinical participants, the balance between managing scarce resources, such as major pieces of equipment and indicators of dignity, such as single sex accommodation, were current concerns:

‘We have been bringing on board compliance with delivering same sex accommodation, which underpins privacy and dignity so that people won’t share accommodation with patients of the opposite sex unless it’s due to clinical need – ITU, CCU, HDU – where the equipment dictates where they go. We try to put them in cohort groups as far as possible and use screens and curtains for privacy’ (PCT contracts manager, 8).

Health Survey for England (HSE)

The Health Survey for England normally only covers private households but, in 2000 and 2005 the survey focussed on Older People and a supplementary survey of care homes was carried out which formed the basis of a report on the characteristics of care home residents (summarised in Bajekal, Purdon, Woodgate-Jones and Davies 2002). This is one of the few health status data sets including older people resident in care homes in the UK that sought a large sample; interestingly the analysts report:

‘About half the respondents in care homes could not be interviewed personally because they were cognitively impaired, too frail, or ill at the time of interview. We have therefore assumed that such respondents were in ‘bad’ or ‘very bad’ health when estimating the institutional population prevalence of ill-health’ (Bajekal et al 2002, p 27).

While the HSE is not a data set that can be used to identify elder abuse, it provides a sound profile of the health of community dwelling older people and, if data collection is repeated to include care homes this would make the Survey a reliable backcloth to report and compare health status.

Primary Care Trust (PCT) Data at local level

No Secrets gave local councils (CASSRs) the lead for safeguarding (Department of Health, 2000), and there have been many concerns that the NHS at primary care level has not generally integrated its activities more effectively and positively with social services and the police. Draper et al (2009) report work by three primary care trusts (PCTs) in Kent and Medway in developing adult protection expertise and data sharing practice across sectors:

‘Health care professionals are very good at considering issues but not so good at providing written evidence, so each PCT has also incorporated audit processes to identify not only the types and numbers of adult abuse cases, but also to monitor training and reporting systems’. (Draper et al 2009).

As Humphries (2010) notes, the proposed moves in commissioning responsibilities from PCTs to GP consortia may challenge local safeguarding arrangements with a lack of clarity in the new groupings as to their role in data collection and management.

4. Regulatory bodies

National regulatory bodies across health and social care collect and report on abuse data, although not all is amendable to further analysis.

Care Quality Commission (CQC)

The CQC was established by section 1 of Health and Social Care Act 2008. It has taken over the work of the Commission for Social Care Inspection (CSCI), the Healthcare Commission and the Mental Health Commission. The Healthcare Commission, also known as the Commission for Healthcare Audit and Inspection, had previously, in 2004, taken over the work of the Commission for Health Improvement.

The CQC has responsibility for monitoring the Mental Capacity Act (2005) Deprivation of Liberty Safeguards provisions (MCA DoLS) which relate to restraint and lawful restriction of liberty within care home and hospital settings for people lacking mental capacity in England and Wales. Data provided to the DH about DoLS are emerging and detail the characteristics of people for whom applications have been made and for whom applications have been granted, such as age, disability, location and length of authorisation. Three funded research studies are investigating elements of DoLS and MCA processes which will produce findings in 2011 and beyond (Clare and colleagues on the interface of the MCA and Mental Health Act (University of Cambridge); Langan and her colleagues on DoLS (University of Bristol) and Ward and colleagues on best interests decision making (University of Bristol and partners). (A study by Brown and colleagues (Salomons Centre) on best interests decisions in complex cases, funded by the Office of the Public Guardian, is due to report in 2011.)

CQC inspectors may visit hospitals and care homes; interview people accommodated in hospitals and care homes; and inspect, or require, the production of, records relating to the care and/or treatment of those people who are deprived of, or at risk of being deprived of, liberty. Inspections usually take place as part of a routine inspection of any given hospital or care home but specific inspections can be undertaken ‘as appropriate’. CQC must provide an annual report as soon as possible after each financial year.

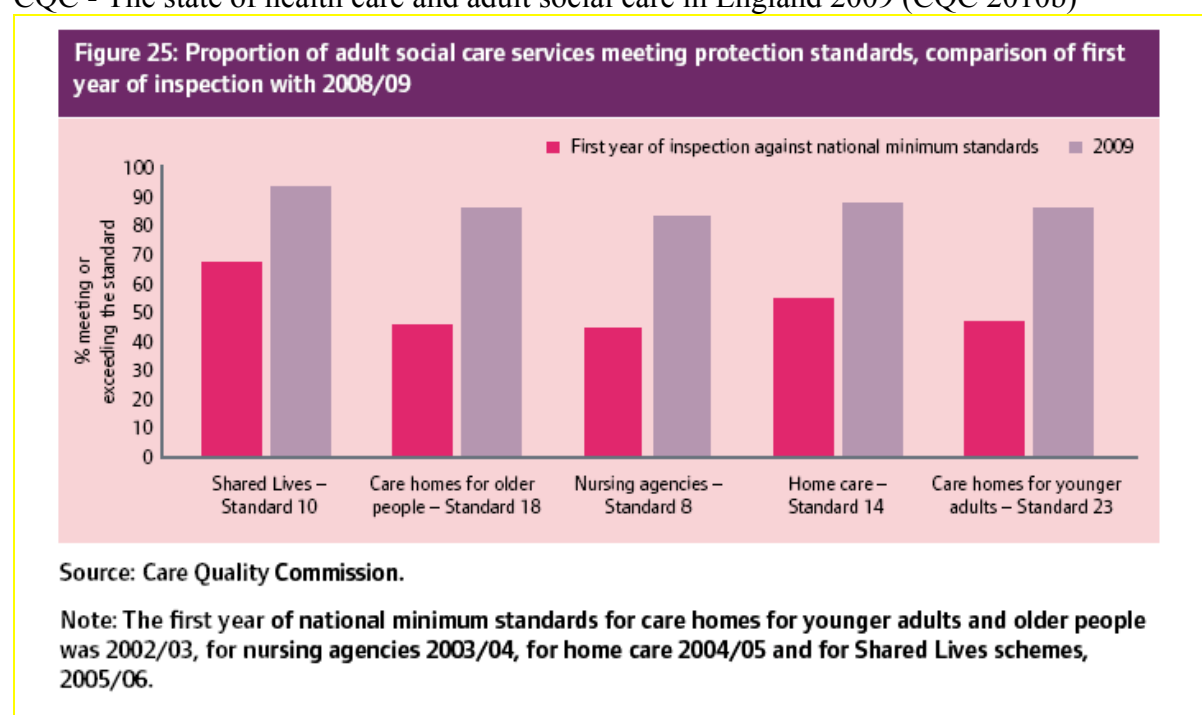
Although CQC can receive individual complaints it cannot investigate them. Like its predecessor, the CSCI, CQC indicates that “If you would like to make a complaint about a care home or service you should contact your provider in the first instance”. Its first annual report does not seem to report the level and nature of complaints received so does not provide direct data on abuse and neglect in care homes or hospitals. It does not seem to generate the “complaints statistics” produced by one of its predecessors, the CSCI. The CQC annual report declares, however, in its five year strategy, that it will “*pay particular attention to the needs and rights of more vulnerable groups.*” (CQC 2010a).

In 2009-10 the CQC carried out 11,477 inspections of establishments providing adult social care services and 741 of establishments providing independent health care under the Care Standards Act 2000. CQC also carried out inspections of NHS trusts under the Social Care Act 2008, children’s services and services for young offenders. It served 536 legal notices and successfully prosecuted 8 organisations. (CQC 2010a)

In addition to its annual report, CQC publishes reports to parliament. In *The state of health care and adult social care in England 2009* (CQC 2010b) the CQC notes that a small proportion of healthcare and social care services were falling below minimum standards with

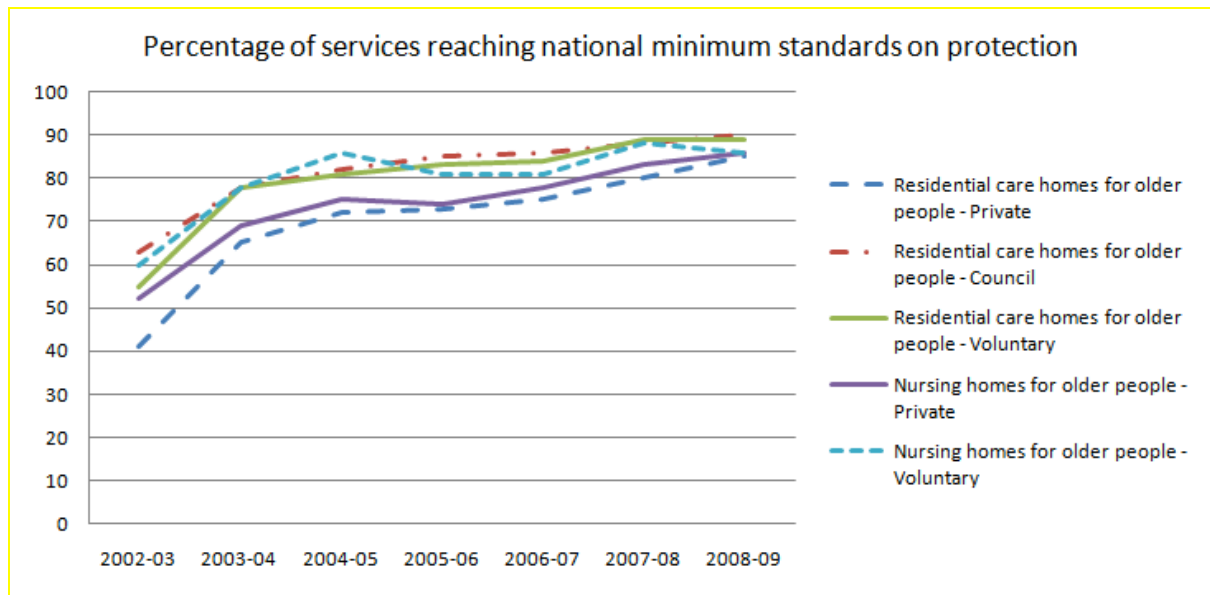
safety, safeguarding and staff training being of particular concern. “In both health and adult social care, concerns have been raised about the effectiveness of safeguarding arrangements across and between different organisations”.

CQC - The state of health care and adult social care in England 2009 (CQC 2010b)



Across the five service types shown, 3,268 services did not meet safeguarding standards.

A more focussed publication, *The quality and capacity of adult social care services*, (CQC 2009) reports the percentage of residential and nursing care homes for older people reaching national minimum standards on protection.



Source: CQC 2009, The quality and capacity of adult social care services 2008/9

Regulation 37 of the Care Homes Regulations 2001 is designed to ensure that all serious incidents occurring in care homes in England are reported to the CQC.

Notification of death, illness and other events

37. - (1) The registered person shall give notice to the Commission without delay of the occurrence of -

- (a) the death of any service user, including the circumstances of his death;
- (b) the outbreak in the care home of any infectious disease which in the opinion of any registered medical practitioner attending persons in the care home is sufficiently serious to be so notified;
- (c) any serious injury to a service user;
- (d) serious illness of a service user at a care home at which nursing is not provided;
- (e) any event in the care home which adversely affects the well-being or safety of any service user;
- (f) any theft, burglary or accident in the care home;
- (g) any allegation of misconduct by the registered person or any person who works at the care home.

(2) Any notification made in accordance with this regulation which is given orally shall be confirmed in writing.

If a serious incident is reported to the CQC under Regulation 37 of the Care Homes Regulations, it is followed up by the CQC regulation inspector or regulation manager associated with that service. Depending on circumstances, they may refer the matter to a specialist inspector. Incidents reported under Regulation 37 are not necessarily abuse and while recorded by the CQC are not published as a matter of course but may be revealed as a result of a freedom of information request or a parliamentary question (see below). CQC might argue, in response to a freedom of information enquiry on abuse in care homes, that the staffing needed to extract the data would be disproportionate.

Helen Southworth (Warrington South, Labour)

To ask the Secretary of State for Health pursuant to the answer of 19 January 2009, Hansard, columns 1202-3W, on prescriptions, on how many occasions there has been a report of (a) an incident of overdose with a controlled drug and (b) other serious incidents reported to the Commission for Social Care Inspection involving a resident in a care establishment in Warrington; and to which individual service each report was made.

Phil Hope (Minister of State (Care Services; Minister for the East Midlands), Department of Health; Corby, Labour)

The requirement for care homes to report incidents to the Commission for Social Care Inspection (CSCI) is set out in the Care Home Regulations 2001. Regulation 37 requires reports to be made to CSCI without delay of:

- The death of any service user;
- The outbreak in the care home of any serious infectious disease;
- Serious injury to a service user;
- Serious illness of a service user (other than in a nursing home);
- Any event in the care home which adversely affects the well-being or safety of a service user;
- Any theft, burglary or accident in the care home; and
- Any allegation of misconduct by the registered person or a worker at the home.

If a serious incident is reported to CSCI under Regulation 37 of the Care Homes Regulations, which governs notification of death, illness and other events in care homes, it is followed up by the CSCI regulation inspector or regulation manager associated with that service. Depending on circumstances, they may refer the issue to the pharmacist inspector. It is one of CSCI's referral criteria to contact a pharmacist inspector and this may result in inspection of the care home and a resulting report with requirements and recommendations. If the overdose is a result of an incorrect prescription from the general practitioner, the pharmacist inspector will liaise via the local intelligence network through the national health service accountable officer at the relevant primary care trust, who will deal with the issue.

We are informed by CSCI that there were 2,716 notifications to CSCI under Regulation 37 of incidents in care homes in Warrington in the years 2006 to 2008. The following table shows a breakdown of numbers of notifications between care homes. We are informed by CSCI that to extract the incidents involving overdose with a controlled drug from these notifications would involve disproportionate cost.

Notifiable incidents under Regulation 37 (The Care Homes Regulations 2001)—care homes in Warrington

<i>Care home name</i>	<i>Current status</i>	<i>2006</i>	<i>2007</i>	<i>2008</i>
Apple Court Care Home	Registered	23	25	26
Arlington House	Registered	4	—	3
Autism Initiatives—Lilford Court	Registered	—	—	2
Booths Hill House	Registered	39	24	39
Brookfield	De-registered	14	15	6
Brookfield	Registered	—	—	12
Calls Care Home	Registered	56	70	54
Cotebrook	Registered	5	2	2
Green Park Care Home	Registered	—	—	—18
Green Park Care Home	De-registered	61	76	31
Heathercroft Care Home	Registered	20	31	39
Heathfield	De-registered	7	—	—
Heathfield Residential Home	Registered	5	21	11
Heath Lodge	De-registered	—	19	9
Heath Lodge	Registered	—	—	13
Heathside	Registered	20	20	5
Heathside Mews	Registered	1	5	13
High Peak Nursing Home	Registered	26	23	21
Holcroft Grange	Registered	26	28	27
Hollybush Care Home	Registered	16	26	21
Houghton Hall	De-registered	38	27	—
James Phoenix House	Registered	1	2	2
Keate House	Registered	26	38	46
Lodge Lane Nursing Home	Registered	4	16	5
Meadow View Nursing and Residential Home	Registered	12	29	38
Old Rectory Nursing Home—Warrington	Registered	8	7	8
Padgate House	Registered	42	54	62
Radcliffe Meadows Mental Nursing Home	Registered	2	11	2
Riverbank Nursing Home	Registered	153	129	112
Rose Villa	De-registered	1	—	—
Rosevilla Residential Home	Registered	6	7	—
St. Marys Continuing Care	Registered	27	25	12
St. Oswalds House Nursing Home	Registered	24	46	12
Summerville Nursing Centre	Registered	—	20	42
Summerville Nursing Home	De-registered	26	1	1
The Glen Deregistered	De-registered	1	—	—
Thelwall Grange Nursing and Residential Home	Registered		4	15
Thelwall Grange Nursing and Residential Home	De-registered	11	8	—
The Old Vicarage Nursing Residential Care Centre	Registered	13	12	13
Three Bridges Nursing and Residential Home	Registered	18	42	21
Three Elms	Registered	31	26	21
Warrington Community Living—Twiss Green	Registered	8	3	5

The CQC has also taken over the responsibilities of the Mental Health Act Commission (MHAC) which produced a comprehensive biennial report on the treatment of people detained under the Mental Health Act 1983. However, it is not responsible for the application of the Mental Capacity Act 2005 in regulated services except its Deprivation of Liberty Safeguards provisions.

The biennial report from the MHAC highlighted interesting features, such as, for detained patients, a higher proportion of unnatural deaths are of patients from ethnic minority groups, compared with natural deaths and around 20 detained patients per year have died of 'natural causes' within one week of receiving ECT (older people are a substantial group of those receiving ECT). Although describing individual cases of poor treatment of older patients, it has not been a source of general or standardised data on the abuse, mistreatment and neglect of older people in care homes and hospital.

The CQC also carries out special reviews. Its predecessor, the Commission for Social Care Inspection (CSCI), published one such review *Safeguarding adults: A study of the effectiveness of arrangements to safeguard adults from abuse* (CSCI 2008). This focused on adult safeguarding processes in the main.

The CQC is currently (2010-11) carrying out a review '*Meeting the healthcare needs of people in care homes*' 2009/10. The review, and an accompanying survey, appears to be looking at overall levels of service provision rather than the incidence of abuse or neglect. The review is investigating how well the healthcare needs of people living in care homes are being met. It will include the healthcare needs of people of all ages living in care homes by investigating whether residents in care homes: have equal access to NHS services; have choice and control over their healthcare; receive healthcare that is safe and respects their dignity. It will also look at how: care is planned and assessed; health is promoted; people are referred to NHS services; health services charge for treatment; consent issues are addressed; healthcare treatment is delivered in partnership with other services.

In addition, the review will investigate: the provision of community health services to care homes; the input from general practitioners (GPs) to care homes; the role of the care home itself, including the skills of care home staff in terms of carrying out delegated healthcare tasks and the role of Primary Care Trusts (PCTs) and councils as commissioners.

Since February 2010 the CQC has been collecting additional evidence from PCTs and councils through a national survey. Starting in October 2010 CQC will be assessing a number of areas that this evidence suggests to be most at risk of poor performance. During the assessment CQC will visit a sample of care homes and will undertake a number of inspection activities, including talking to care home managers and staff. To reiterate, the survey will look at overall levels of service provision rather than the occurrence of abuse and neglect.

On present showing, the CQC does not and may not in the future provide direct data on the occurrence of abuse and neglect in care homes and hospitals unless it carries out a special review or if elder abuse and neglect are seen as synonymous with poor care. Nor is information on individual care home closures and the reasons for these, readily identifiable. However, as sections above have discussed, this is a time of immense sector change. One representative of the care home sector interviewed for this study reflected:

‘Care homes don’t provide, and have never provided, data direct to the DH because they have not been subject to monitoring in the same way that the NHS has but now we have CQC which has brought three regulators together, we are now in a period of significant change in terms of how the regulators operate and that hasn’t all shaken down yet. So we don’t know what effect that is going to have on the social care sector yet. Essential Standards of Safety and Quality are clear links to the regulations and clear outcomes that are expected and clear protocols and policies. Organisations have their own local policies and protocols that link with the Safeguarding Boards and they should be aware of local policies.’ (Care home sector representative, 12).

The interview with three officers of the Care Quality Commission (CQC) confirmed their impression and experiences of cultural differences between the NHS and independent sector:

‘... pressure sores, malnutrition and lack of hydration ... in the NHS in cultural terms abuse may be conceptualised as a mistake to be learned from ... [social care services regulated by CQC] would be more ready to conceptualise something as potential abusing and refer to safeguarding for further investigation. The way forward is to [look at how] health and social care information is gathered and managed and disseminate information through a consistent approach across the health and social care economy (CQCa, 13).

The CQC worked with its predecessor organisation the CSCI to harvest the information collected on the safeguarding forms to ensure information would be available to the CQC centrally. Some of its early work was directed to: *‘Making sure there is continuity of data and that data collection meets the needs of the future as well as the present’* but its officers describe CQC work as early in its development: One recent activity has been (in June 2010) the publication of a protocol (developed between the Association of Chief Police Officers, the Association of Directors of Adult Services and the CQC) to set out how CQC will work with other agencies to ensure that people who use care and other services are safeguarded from abuse:

‘That’s not a joint document. That’s really more an internal document for our staff to say this is our role in safeguarding and we recognise that we need to do further pieces of work with ADASS and NHS organisations in developing further joint guidance and that’s where the threshold work would fit as well’ (CQCb, 13)

The CQC has designed a dataset and has decided how to gather data. It sees a need for the ADASS and other regulatory authorities to agree to this. It is aware that when the CQC passes an alert to a local authority it is up to the local authority whether they accept it or to take it on. Even if this is not taken on, the CQC might still have an interest in whether the law has been complied with or not and their decision is important evidence that might be used in specific situations. For the CQC there is a difference between a safeguarding and a regulatory issue and this affects what they count and why they do this. Speaking of a possible incident, one of the CQC officers noted:

You may need to triangulate evidence from a number of sources so whether it was dealt with as a safeguarding issue and outcome of the local authority work is one of the pieces of evidence in deciding whether the law was being complied with (CQCb, 13).

A universal set of essential ‘standards’ of quality and safety was introduced on 1 October 2010 which all registered health and care providers must meet. The essential standards describe the standards that people should experience to comply with the law, but, as a CQC officer noted, ‘how you write this up as an algorithm that you can use logically and consistently is very difficult’ (CQCc, 13).

Currently, the CQC receives notifications from the NHS and other registered providers about a series of defined events that includes whether people have come to unnecessary harm. This obligation extends to NHS services and there is a special provision in the law that enables people to make notification to NPSA and on to CQC so that any which have been associated with safeguarding are given particular significance in the data received by the CQC. The CQC officers portrayed this as a positive move to ensure that they were notified of incidents more consistently although they were not oblivious to the difficulties of this:

‘As time progresses, the CQC approach on treatment of all information from health and social care will become more refined. Health and social care will become more refined. We are new to it in terms of being regulator of health and social care and it’s not entirely clear as to what common approach can be taken to both sets of information. As a single regulator we need a commonality of approach as far as this is practical to do so.’ (CQCb, 13)

It is evident that the CQC and the NPSA (see below) have some parallel methods, such as quality and risk profiles. There are differences, of course, in that the CQC role applies to regulated services (but not supported living where there is no personal care, and there are currently grey areas about their role with services such as extra care housing). CQC will scrutinise an abuse referral to decide whether the regulations and essential standards are being complied with and also how to deal with the situation (possibly exploring criminal or civil action). We recommend that the CQC sets out its data collection processes around safeguarding in the public domain and investigates the potential for these to be subject to secondary data analysis. The management of Regulation 37 data could thereby be explained and hopefully supported by other stakeholders. This data should not be seen as synonymous with cause for concern, given the policy aspiration for more people to die in the location of their choice, which for many older people may be care home rather than hospital settings.

NHS governance data

Terms and Definitions

Following the *No Secrets* review, the DH (2010d) developed guidance on Clinical Governance and Adult Safeguarding- An Integrated Process. This guidance presents terms and definitions that appear to be seeking some common language, a selection of which is presented below. Interestingly, in the interviews with participants in this research many of these terms were used interchangeably, particularly around the term ‘incident’; thus there may be scope for the continued encouragement of adopting common terms and definitions:

- **Event:** The term ‘event’ is used to signify any incident or occurrence that has the potential to cause harm and/or has caused harm to a person or persons. This might happen as a consequence of an intervention, relating to a piece of equipment and/or as a consequence of the working environment.

- **Serious Incident:** a Serious Incident requiring investigation is defined as an incident that occurred in relation to NHS funded services and care resulting in; unexpected or avoidable death, permanent harm, a scenario that prevents a provider organisation's ability to continue to deliver health care services, a person suffering from abuse, Never Events: (a serious event, that should 'never' happen to a patient) (defined as a largely preventable patient safety incident that should 'not occur if the available preventative measures have been implemented by healthcare providers) and adverse media coverage. (see NPSA National Framework for full definitions):

<http://www.npsa.nhs.uk/nrls/reporting/patient-safety-direct/>

- **Complaint:** In general use, a complaint is an expression of dissatisfaction. All complaints should always be considered in relation to safeguarding particularly when the complaint involves poor care, poor care culture, neglect or omissions.

- **Patient Related Incident:** A patient incident is an incident that has occurred in an environment where health care is provided. It may be as a result of prescribed or unprescribed care, administration of procedures and interventions. For example 'trips' and 'falls', a medication error, shortage of staff, incorrect procedure, an episode of aggression, unsafe storage of equipment etc.

- **Significant Event:** A significant event is a term used by GP's to describe a positive or negative incident that has occurred in primary care and is similar to a patient incident report. (Source DH 2010d)

In illustration of this, a patient incident officer in a PCT made the following distinction between patient safety and safeguarding:

'My personal view is that generally speaking there is very little difference between safety and safeguarding – by being a safety issue it is a safeguarding issue so if you have a patient fall in an acute setting this is both safety and safeguarding; medication errors are safety and safeguarding. You could take a purist view of safeguarding if it is institutional abuse, or is it safeguarding ensuring that institutions are safe for patients and they are actually following their duty of care?' (9).

Council for Healthcare Regulatory Excellence (CHRE)

The CHRE regulates (oversees and monitors) the regulators. Under the NHS Reform and Health Care Professions Act 2002 and the Health and Social Care Act 2008, CHRE has the powers to carry out the following activities:

Monitoring how the health professions regulators carry out their functions

Every year CHRE carries out a performance review with each regulator. The review looks at how the regulators carry out their functions against agreed standards. It highlights good practice and identifies issues that might benefit from a co-ordinated approach.

Referring cases to court where decisions are considered too lenient

When concerns about the conduct or performance of a health professional are referred to a regulatory body, the regulator carries out an investigation to determine whether the concerns are valid and whether the professional should continue to practise.

CHRE looks at the final stage decisions made by the regulators on professionals' fitness to practise. If a decision is deemed unduly lenient and fails to protect the public interest, it can refer the case to the High Court (in other parts of the UK this is to the Court of Sessions for Scotland or the High Court of Justice for Northern Ireland).

In its annual reports, CHRE publishes data on number of referrals and outcomes but not on type of case. Further, In 2007 CHRE published a report on inappropriate sexual contact between health professionals and clients (Halter, Brown and Stone, 2007) as well as notes of guidance for patients and carers (*Clear sexual boundaries between healthcare professionals and patients*) but these too are not a source of data on this topic.

General Medical Council (GMC)

Through its Professional Conduct Committee (PCC) and Fitness to Practise Panels the General Medical Council monitors the conduct of doctors in public and private practice. The GMC reports annually on the number of complaints received about doctors and how those complaints are dealt with at each stage of the fitness to practise procedures.

For the first time, the report for 2009 was supplemented by a series of factsheets on key themes including ethnicity, gender, time since qualification, area of practice and recorded allegations. The report and factsheets are available on the GMC website.

<http://www.gmc-uk.org/publications/7263.asp>

Illustrative summary data from the 2009 report:

In 2009, 270 Fitness to Practise Panel hearings took place compared with 204 in 2008; 68 doctors were erased from the Medical Register at a Fitness to Practise panel hearing in 2009 compared to 42 in 2008. A further 15 doctors were erased at Fitness to Practise review hearings meaning that a total of 85 doctors were erased from the Medical Register in 2009.

- The most common allegation resulting in erasure from the register in 2009 related to improper relationships with patients - 15 cases in total.
- The most common hearing outcome was suspension - 77 doctors were suspended in 2009.

Allegations are broken down by broad category but there is insufficient detail to identify cases of abuse, mistreatment and neglect. Notes of individual Fitness to Practice panel hearings for individual doctors are published on the GMC website and it might be possible to analyse these in detail on a case by case basis.

http://www.gmc-uk.org/concerns/hearings_and_decisions/data/231.asp

The Kerr-Haslam inquiry (DH 2005) into alleged sexual misconduct by two doctors, in its chapter on Prevalence and Data reported:

‘At present, there seems to be no official database that records crimes committed by doctors (or other health professionals) against patients. Although convicted crimes in the UK are officially recorded and reflected in published statistics, it is impossible to determine from these statistics whether crimes are committed by doctors. And, although the GMC is routinely notified by the police whenever a doctor commits a crime, the GMC does not keep a database of the numbers of doctors who commit crime against patients.’ (DH 2005)

Following the [Shipman Inquiry, 2001-2005](#) (Smith 2004), a major programme of work was set up to reform the UK’s system for the regulation of medicine and professions allied to medicine. The National Clinical Assessment Service (NCAS) had already been established in 2001 (part of the NPSA, see below), to seek to resolve concerns about doctors’ and dentists’ performance. ‘While seeking a non-punitive approach in addressing patient safety concerns, (it will) incorporate a comprehensive strategy for prevention, treatment and rehabilitation for health professionals’ (Ocloo 2010, p514). More recently (February 2010), following recommendation 16 of the Mid Staffordshire NHS Foundation Trust Inquiry (Francis 2010), the DH established a further inquiry into the commissioning, supervising and regulation of NHS bodies (again to be chaired by Robert Francis QC).

General Social Care Council (GSCC)

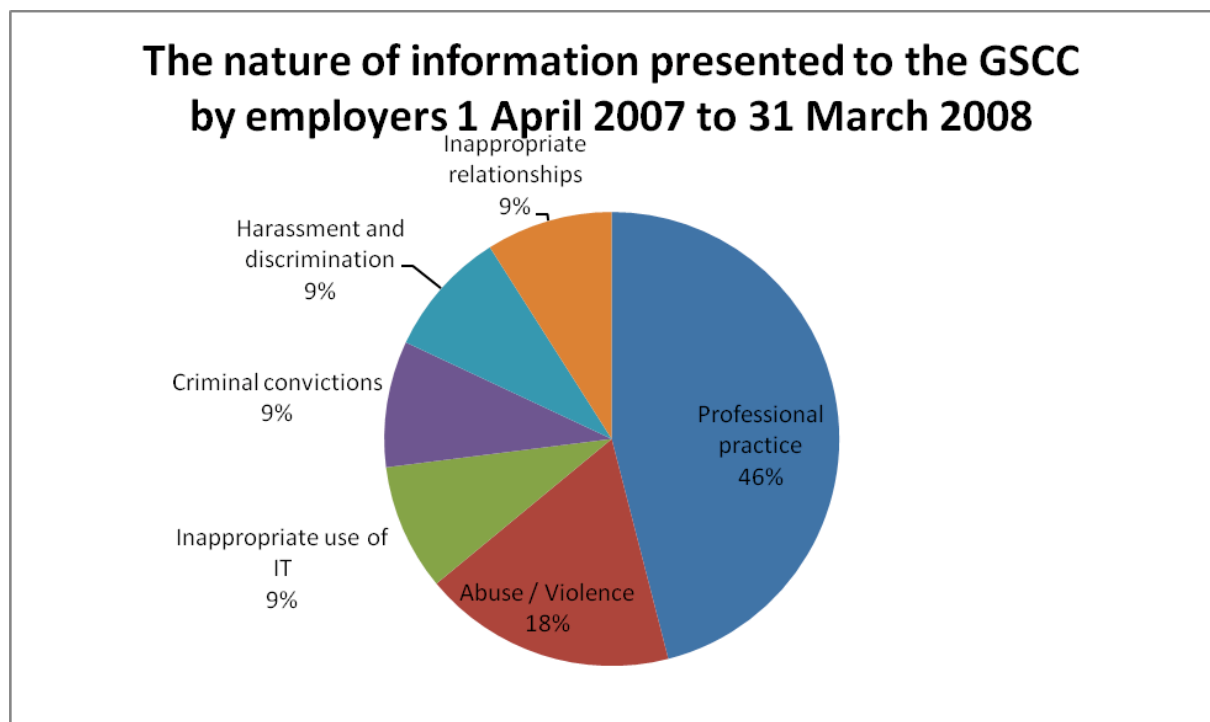
The GSCC is the social work regulator in England registering social workers and regulating their conduct and training. It was set up in October 2001 under the Care Standards Act 2000, charged with ensuring that social work education and training are of a high standard and that only people who are trained, meet the criteria for registration, and committed to high standards are able to work in social work in England. At the time of writing, the GSCC is being closed down and parts of its functions are being transferred to the Health Professions Council (HPC). The GSCC has been unusual as a professional regulator in having Codes of Practice for both practitioners and for their employers.

Cases of misconduct by social workers are handled by the Conduct Group. Cases may be put forward to GSCC by members of the public or by an employer; 28 percent of cases come directly from members of the public. In September 2008 the GSCC published a report summarising conduct cases from 2003 to 2008 (GSCC, 2008). The summary data show the nature of the allegation but not the location (care home etc) nor the age of the victim. Records

of conduct hearings for individual social workers are available on the GSCC website and are lending themselves to detailed analysis on a case by case basis (see McLaughlin 2010):

http://www.gsccl.org.uk/Conduct/Conduct_hearings/recently_concluded_hearings/

Case data are therefore available from GSCC for secondary analysis (unless the hearings are in private) but the small numbers of cases involving adults mean that this analysis is unlikely to reveal levels of abuse or neglect by social workers of older people in care homes or hospitals. What the data may offer however, are pictures of the work of safeguarding (or lack of it) from practice. They also have the potential to reveal that location (eg in care home or in the community) is not a factor of huge significance at all times, for example, cases have involved practice around older people in the process of moving to care homes from community settings. Given that social workers are more likely to be involved at times of major changes in people's lives, such as a move into a care home, location may be less important when considering measuring the prevalence of abuse by these professional than it would be for measuring prevalence of abuse by social care workers. The ages of service users are not generally reported, although may be imputed from the kinds of services involved and the team in which social workers are employed.



Health Professions Council (HPC)

The Health Professions Council regulates 15 health professions: arts therapists, biomedical scientists, chiropodists / podiatrists, clinical scientists, dieticians, hearing aid dispensers, occupational therapists, operating department practitioners, orthoptists, paramedics, physiotherapists, practitioner psychologists, prosthetists / orthotists, radiographers, and speech and language therapists (and shortly social workers will be transferred to the HPC).

The results of individual ‘fitness to practise’ hearing held by the Council’s Conduct and Competence Committee are published on the web site and might be analysable on a case by case basis.

In 2008 HPC commissioned a report to provide an overview of existing research into complaints and their mechanisms, with a particular emphasis on service users’ experiences (Gulland, 2009). This report noted that complaints against non-medical professionals form a very low proportion (5%) of the total.

Cases by profession and complainant type – 2008-9

Profession	Article 22(6) / anon	Employer	Other	Police	Public	Registrant / professional	Total
Arts therapists	1	5	0	0	1	1	8
Biomedical scientists	17	20	0	2	1	6	46
Chiropodists / podiatrists	2	11	4	7	28	10	62
Clinical scientists	1	3	1	0	1	2	8
Dieticians	0	0	0	0	1	0	1
Occupational therapists	4	34	1	2	12	2	55
Operating department practitioners	14	25	1	5	2	8	55
Orthoptists	0	0	0	0	0	0	0
Paramedics	17	47	0	8	15	12	99
Physiotherapists	5	30	6	7	37	10	95
Prosthetists / orthotists	0	1	0	0	2	3	6
Radiographers	3	17	1	5	6	2	34
Speech and language therapists	0	9	2	0	3	0	14
Total	64	202	16	36	109	56	483

Source: HPC Fitness to Practice Annual Report 2009

The overall results of HPC fitness to practice hearing are published in its Fitness to Practise Annual Report. The 2009 Annual Report shows allegations that have resulted in a case to answer decision have included: attending work whilst under the influence of alcohol; bullying and harassment of colleagues; conviction for possession of indecent images of children;; inappropriate relationships with patients / clients; ongoing lack of competence; poor record keeping; self-administration of drugs whilst at work; theft of controlled drugs; and working whilst on sick leave.

The abuse, neglect or mistreatment of patients does not appear in the above list although ‘Rude behaviour towards a patient’, ‘Inappropriate treatment of patients’ and ‘Caused injuries to a patient’ were cited in cases where there was ‘no case to answer’.

The published complaints data do not indicate the age of the patient or the location of the alleged misdemeanour so will not lend themselves to the analysis of the abuse, neglect or mistreatment of older people in care homes or hospitals.

Nursing and Midwifery Council (NMC)

As with the GMC and the HPC, the NMC carries out 'Fitness to Practise' hearings following complaints about its registrants and publishes the results of these hearings in an annual report. In 2008-9 the NMC received 2,178 allegations of which 1,759 were referred to the investigating committee.

Sources of new allegations

Source	2007-8	2008-9
Employers	53.13%	47.95%
Police	28.92%	23.17%
Members of the public	8.81%	16.83%
Other health professionals	2.22%	1.53%
Others (including self referral)	6.92%	10.52%

Source: NMC Fitness to Practise Annual Report, 2008-9

The NMC annual report provides an analysis by type of allegation – which includes patient abuse. Sexual abuse may be in this or the 'other' category.

Conduct and Competence Committee allegations (including legacy allegations considered by the Preliminary Proceedings Committee)			
Description of allegation	2006-2007	2007-2008	2008-2009
Dishonesty*	19.23%	17.32%	14.83%
Patient abuse (physical, sexual, verbal, inappropriate relationship)	17.09%	14.30%	8.37%
Lack of competence	-	-	8.66%
Failure to maintain adequate records	7.48%	10.37%	8.52%
Incorrect administration of drugs	10.47%	9.87%	11.75%
Neglect of basic care	10.04%	9.16%	10.57%
Unsafe clinical practice	7.48%	7.75%	7.78%
Failure to collaborate with colleagues	4.06%	6.95%	6.90%
Colleague abuse (physical, sexual, verbal, inappropriate relationship)	4.27%	2.72%	1.91%
Failure to report incidents	3.42%	2.62%	0.44%
Failure to act in an emergency	3.21%	1.91%	2.06%
Accessing pornography - adult	2.35%	1.01%	0.59%
Violence (harassment, assault)	1.92%	1.41%	1.91%
Other**	8.98%	14.60%	15.71%

*Dishonesty includes theft, fraud, false claim to registration, claiming sick pay fraudulently, falsification of records, failure to disclose previous convictions, sleeping on duty, dishonesty about previous employment and misappropriation of drugs.

** Other includes absence without leave, drink and drugs related offences (other than incorrect administration), breach of confidentiality, conviction or caution, bullying, failure to communicate, failure to maintain adequate staffing levels, failure to obtain consent, failure to provide adequate nursing care, failure to respect dignity of patient, holding against their will, indecent exposure, and sexual abuse.

Source: NMC Fitness to Practise Annual Report 2008-9

In summary, the 1759 allegations considered by the Preliminary Proceedings Committee for 2008-2009: related to:

- Dishonesty – 14.83%
- Patient abuse (physical, sexual, verbal, inappropriate relationship) – 8.37%
- Lack of competence – 8.66%
- Failure to maintain adequate records – 8.52%
- Incorrect administration of drugs – 11.75%
- Neglect of basic care – 10.57%
- Unsafe clinical practice – 7.78%
- Failure to collaborate with colleagues - 6.90%
- Colleague abuse – 1.91%.

The Nursing and Midwifery Council also records the setting of the allegation.

Conduct and Competence Committee settings of allegations			
	2006-2007	2007-2008	2008-2009
NHS	46.67%	42.48%	43.72%
Residential or nursing home	25.81%	30.07%	20.88%
Unknown*	15.32%	13.89%	21.59%
Other settings**	6.85%	8.82%	9.38%
Private hospital or company	5.39%	3.84%	3.01%
Agency	3.23%	1.14%	1.06%

* In conviction or caution cases the work setting of the registrant is not always known or relevant.
 **Other settings includes independent practice.

Source: NMC Fitness to Practise Annual Report 2008-9

The more detailed data on complaints held by the NMC may well lend itself to secondary analysis to examine incidents of mistreatment, abuse and neglect in care homes and hospitals, although the data may not easily identify the age of the victim.

The NMC also publishes the results of individual disciplinary hearings and these may lend themselves to further, quantitative and qualitative analysis and review. A recent Fitness to Practice Report reported:

‘Many allegations directly involve patients and most commonly these allegations concern instances of physical or verbal abuse and failure to communicate and respect and dignity of patients. Most cases concern a number of instances and have involved more than one type of allegation’ (NMC, p 12).

However, there may be limits to measuring professional data across sectors and roles, The NMC participant in this study noted:

‘Allegations around nurses' and midwives' fitness to practise (FtP) are completely specific to each person and each act they are alleged to have done or failed to do. The categories of allegations in our annual reports are our own internal categories devised to put some shape around the hundreds of different allegations. We collect information about allegations of abuse but not specifically abuse of older people’.
 (14)

Furthermore, NMC work concerned with safeguarding draws on information collected and interrogated by others:

‘When an allegation is made against an individual nurse or midwife, this comes to the Practice Directorate and team to be looked at, to go through the processes and get to hearing. And in that process we would uncover what had occurred but that’s usually after an investigation has taken place in the place of employment. Data is second hand by then because, for abuse in its broadest sense, you would know about individual incident reports. The NMC regulates individuals in systems. The allegation could be for any setting or could be about anyone...

We don’t use definitions of abuse. Judgements will be made against the (NMC) Code - dignity and respect - and then whatever is presented in front of the panel, e.g. if there was no dignity and respect given to a patient, this would form the basis of the judgement made. Decision on whether there is substance and once it’s in the process everything’s down to the NMC then we are concerned ‘*have the standards that we expect been held up or not?*’ Solely measured against The Code. So all the other data we don’t utilise’. (14)

During the course of this study the NMC Safeguarding Adults project was set up through the DH (launched on 13th October 2010). This aims to reinforce the NHS and safeguarding links around the *No Secrets* guidance with materials for individual professionals working in health and social care. In essence the NMC came to the view that the support doctors are given to recognise and deal with abuse (such as the online materials on confidentiality in situations where abuse is disclosed produced by the General Medical Council, no date) should be available similarly to nurses. The NMC itself had conducted a quick survey in June 2010 asking how comfortable nurses and midwives feel about discussing abuse. Despite its short timescale of three weeks this was reported to have received 1,400 responses that identified their uncertainties in the subject (participant 14). The NMC participant interviewed for this study felt that this ‘said something’ and outlined the areas of NMC development:

‘Threshold and tolerance and acceptance for poor practice – talking over a patient – now including in safeguarding paper to corporate leadership on what safeguarding means as a specific legal for us directly related to our legislation for fitness to practice. These resources are directed at nurses and midwives to support in practice, raise awareness – this does happen. You need different ways of recognising the signs, not only do we want you to recognise but we want you to do something about it. Make appropriate referral to take appropriate action. Make sure the loop is closed – don’t leave it for someone else to do.’ (14)

5. Data from individual incidents

Individual incidents of abuse and neglect can be reported in a number of different ways, dependent mainly on the setting. While these can be useful sources for secondary analysis, data reported are often inconsistent and definitions vary.

Serious case reviews

Serious Case Reviews (SCRs) in respect of vulnerable adults are inquiries conducted by Adult Safeguarding Boards at local level when harm or death has occurred; until recently they have been little scrutinised. Despite the interest in local adult SCRs among the adult safeguarding community, there has been little exploration of their content, process, analysis or recommendations. Brown (2009) recently reported on her observations as an independent chair covering eight adult SCRs across a small number of local authority areas, particularly in Kent where procedures have long been in place. Kitson (2009) also identifies some lessons arising from publicly available national reports (not all SCRs) into deficiencies in the care and treatment of vulnerable adults in institutional settings.

One analysis of 22 SCR reports (Manthorpe and Martineau 2010) explored:

- The rationale for SCR; detail of victim(s), alleged abuser(s) and setting(s)
- Form of Abuse (covering also neglect) using the categories outlined in *No secrets* (DH 2000)
- Threshold of SCR (if this was expressly considered) – the reason why a SCR was felt to be appropriate
- Review personnel
- Purpose(s)
- Methodology or processes
- Cost
- Timescale
- Lessons / recommendations
- Follow up / action plan
- Reflections on SCRs.

These reflections on the role and function of SCRs were provided in the context of the review (DH 2008; 2009) of *No Secrets* which received calls for the activity of SCRs to be more consistent and for lessons learned to be more widely circulated among social workers, other professionals, regulators and policy makers. In contrast to SCRs in relation to the deaths of or serious harm to children and to mental health inquiries where reports are publicly available, because adult safeguarding SCRs are not public documents there have been few opportunities to consider them collectively, as occurs regularly in respect of children's SCRs and mental health inquiries.

In addition, there is a wealth of analytical material and also much commentary exploring health related investigations and Patient Safety concerns. Some of this relates to subjects covered in serious case reviews. For example, the Healthcare Commission (HC, precursor of the CQC) highlighted threats to patient safety in the report *Learning from Investigation* (HC

2008); as being in the areas of leadership, management and targets, governance and the use of information, the impact of mergers and organizational change, safeguarding vulnerable adults, and poor care of patients on general wards (HC 2008).

One recent case concerns the murder of four older women in hospital. In March 2008, staff nurse Colin Norris received a prison sentence of a minimum term of 30 years following his conviction for the murder of four patients and the attempted murder of a fifth in 2002 at Leeds Teaching Hospitals NHS Trust (LTHT). Over six months from May to November 2002, Norris injected insulin into five non-diabetic patients, who had surgical repairs of hip fractures. The patients suddenly became severely hypoglycaemic, resulting in brain damage, which was either the cause or a significant contributor to their deaths. The Strategic Health Authority inquiry (YHSHA -Yorkshire and the Humber Strategic Health Authority- 2010a) notes that while adult safeguarding systems were not in place at the time of what were seen as Serious Untoward Incidents, there have been developments:

‘LTHT has taken steps to address the requirements of the ‘No secrets’ guidance on adult safeguarding. Significant progress was made with the establishment of Trust procedures and a steering group in 2006 and at this time the procedures were reflective of the 2000 guidance. The procedures were further updated in 2007. There has also been the appointment of a Nurse Consultant and Lead Nurse with the responsibility to lead on safeguarding for the Trust.’ (YHSHA 2010a, p21)

From the same Strategic Health Authority, another independent inquiry report commissioned by NHS Yorkshire and the Humber, declared that it was unlikely that Sister Anne Grigg-Booth, a senior night nurse practitioner (NNP) at Airedale NHS Trust, ‘deliberately set out to harm patients’. The report into incidents that took place between 2000 and 2002, declares that she “was not a Beverley Allitt or Colin Norris in that her actions were almost entirely open”. Notwithstanding this, Grigg-Booth had been charged with three offences of murder, one offence of attempted murder and 13 offences of administering noxious substances with the intention of causing harm. She died before her trial in 2005. Despite the inquiry’s views of a lack of intent, it is scathing in its criticism of the hospital culture, clinical governance systems and management. It notes, for example:

‘The night staff in particular appeared to operate in a vacuum, separated from the world of day staff, save for brief handover arrangements for continuity of patient care. The normal arrangements for ensuring their involvement in management meetings and professional briefings appeared to be deficient and the supervision, challenge and professional support offered to Sister Grigg Booth and the NNPs (night nurse practitioners) was woefully inadequate. Of great concern is the fact that they were effectively left to their own devices’ (YHSHA 2010b, p130).

Independent Safeguarding Authority (ISA)

The House of Commons Health Committee report on Social Care (March 2010) summarised stages towards the establishment of the Independent Safeguarding Authority:

‘In 2004 the DH launched the Protection of Vulnerable Adults (POVA) scheme, whereby prospective care workers could be checked, as part of Criminal Records Bureau (CRB) Disclosure, against a list of care workers who had harmed vulnerable adults in their care. This was mandatory in respect of adult placement schemes, domiciliary care agencies and care homes. People employing PAs using Direct

Payments were not required to obtain CRB Disclosure, but had the option to request it.

In October 2009 the POVA list became the Adults Barred List and the scheme was replaced by Adult First Check, both operated by the Independent Safeguarding Authority (ISA), a new non-departmental public body.

From July 2010 a completely new system will be implemented. All individuals in England, Wales and Northern Ireland working or volunteering with vulnerable adults or children in the education, care and health sectors will be required to register with ISA under the new Vetting and Barring Scheme (VBS). Individuals will be required to pay £64 to be registered with ISA in England. The VBS will apply to homecare workers, but not to PAs¹

On the change of government, the Coalition Government, elected in May 2010, set out its aim to 'review the criminal records and vetting and barring regime and scale it back to common sense levels'. Plans to begin registration were therefore postponed indefinitely while the review was being carried out. A parallel review of the Criminal Records Bureau is also being undertaken, with very similar aims. The ISA review's terms of reference are very open, and include an examination of whether any vetting and barring scheme is needed, as set out by the Home Secretary (Home Office, 2010):

- Considering the fundamental principles and objectives behind the vetting & barring regime, including;
 - Evaluating the scope of the scheme's coverage;
 - The most appropriate function, role and structures of any safeguarding bodies and appropriate governance arrangements;
 - Recommending what, if any, scheme is needed now; taking into account how to raise awareness and understanding of risk and responsibility for safeguarding in society more generally.

The ISA is still in its infancy. However, given the historical data on people who were placed on the POVA List, who were mostly transferred to the Adult Barred List, the ISA remains a source of specific data about people who are barred, what harm and misconduct leads to someone being barred and the kinds of settings they were working in. This is a unique slice of the picture, which provides a useful indication of the kinds of harm and abuse caused by paid workers (and volunteers). This data, newly covering hospitals, could be an important source of data about referrals and outcomes, but it remains limited in the information it provides about people who have been harmed or placed at risk of harm by staff and volunteers.

Work for the DH being undertaken by the Social Care Workforce Research Unit will include analysis of ISA data when available, similar to the detailed analysis of the former POVA data undertaken by this Unit (Stevens et al 2008). At the time of writing there is discussion about

¹ What this means is that people using direct payments or their own funds to employ personnel assistants, or other workers to provide support, are not legally obliged to check whether these workers are on the Adults Barred List, nor do they have to get a CRB check. However, people in this position are able to make such checks if they choose

the details of access to the data which needs to be negotiated on a project by project basis, as it is highly confidential.

The following information is recorded on the ISA referral form:

1. About the 'Referred person' (i.e. worker accused of harming a service user or placing them at risk of harm)

- Date of Birth
- Gender
- Nationality (not ethnicity)
- Professional status (e.g. whether registered as a social worker)
- Contact details
- Job Role (free text, so not categorised)
- Main duties and responsibilities (free text, so not categorised)
- Qualifications (free text, so not categorised)
- Training in current post (free text, so not categorised)
- Training in previous posts (free text, so not categorised)
- Previous employment
- Prior history of any misconduct, disciplinary action or complaints (free text, so not categorised)
- Current job, role and duties - if still employed/volunteering (free text, so not categorised)
- Reason for employment ceasing: Dismissed, Resigned, Retired

2. About the person making the referral - the 'Referring party'

- Contact details
- Name of organisation
- Type of organisation (free text, so not categorised)

3. About the Harm ('relevant conduct') or why the referrer thinks there is a risk of harm.

- Free text summary of what happened
- Free text description of the harm or risk of harm to child or vulnerable adult
- Whether the referred person has admitted responsibility for the 'relevant conduct' or risk of harm – Yes/No

4. About the child or vulnerable adult

- Contact details
- Date of Birth
- Gender
- Details of any vulnerability – e.g. emotional, behavioural or physical (free text, so not categorised)
- Relationship between the referred person and the person harmed (free text, so not categorised)

5. Progress and outcome of the referral:

- Steps in the decision making process
 - Receipt of referral

- Initial decision whether 'Minded to bar' ie whether a relevant case
- Referred person submits representations
- Final decision about whether to bar or not
- Whether an appeal is launched or not

6. Other information required

- A Chronology of events in relation to the harm

The data are collected on case management software, which means that much work is need to generate aggregate data, although much information is stored. Clearly, the extensive nature of the review of the ISA outlined above is very likely to mean that data recording will change, altering the kinds of data available for secondary analysis.

Local Government Ombudsman (LGO) and the Parliamentary and Health Service Ombudsman

Individual Local Government Ombudsman (LGO) complaint investigations are listed and categorised (e.g. social care) on the LGO website but they do not lend themselves to secondary analysis. The site, and hence the cases, can also be searched but it is a long-winded process which might at best only produce an occasional individual case of care home abuse or neglect. Similarly, cases handled by the Parliamentary and Health Ombudsman are small in number to provide a large source of data on the abuse and neglect of vulnerable older people in care homes and hospitals. The data from such investigations may similarly be more useful on a case by case basis, given that the Ombudsman service is likely to have devoted significant resources to its investigations. In other countries, long-term care ombudsman services may be more similar to UK complaints systems but case records have been used to compile data sets to explore aspects of care home practice (Watson et al 1993).

Personal accounts

As part of the review of the *No Secrets* guidance in early 2009, MIND, the mental health voluntary organisation, was commissioned by the DH to undertake consultation among people whose views might not be heard. MIND circulated questionnaires to a network of 2,000 people with experience of mental distress (members of Mindlink), 180 local MIND associations, and 150 people from black and minority ethnic groups (BMEs) with experience of mental distress (Diverse Minds) (Whitelock 2009). Questions covered experience of abuse, attitudes to personal safety and involvement of statutory agencies. The study received 84 completed questionnaires (3.6% response rate) (Whitelock 2009).

The mixed sampling frame and low response rate mean that this is probably not a good data source for secondary analysis. However, like many personal accounts, it presents a good source of data about individual experiences of formal systems. To the best of our knowledge there has been little synthesis of personal experiences other than those produced by voluntary groups, such as MIND and AEA and more recently in relation to care home experiences by Wells (2009), by the Patients' Association (2010) and by the pressure group A Dignified Revolution (covering hospital experiences in particular) (Dennis 2009). Such reports contain powerful personal accounts and testimonies, particularly from carers. Some have collected numerous stories, and the following extracts illustrate some of these, starting with the account of Elin Styles about the treatment of her mother in-law who had dementia, during the last period of her life in 2009, one of 17 reported by the Patients' Association (2010):

‘The ward was full of elderly people in the same situation and stank of faeces. I never once saw anyone being helped with food or drink....She was always covered in food matter of one sort or the other and in varying degrees of dryness during her stays in the hospital and on many occasions I would ask the staff for a clean nightdress, to be told that someone would change her as soon as possible and end up trying to do it myself. As a rule I would check if she was clean and dry on arrival at the hospital and that was very rarely the case either and I would again have to ask several times and end up having to be quite firm, bordering rude, to get results’.

In the next extract, the focus is on care homes:

‘Care homes are employing people whose indifference to residents’ feelings denies the humanity of the vulnerable folk they are paid to care for. As I have said I witnessed what was happening to the other residents and it is for them and all residents in uncaring care homes that I am campaigning for “Quality Care”.

To gather additional material I have interviewed:

Carers, former carers and visitors to care homes and hospitals.

A professional chef, care workers and day centre staff.

Carers who have experienced poor quality domiciliary care and respite care.

A care worker too scared to name the home where abuse is happening.

Carers who agreed to talk to me provided they were not identified.’ (Wells 2009, p.3)

In one of the few analyses of personal accounts of being harmed in healthcare settings, Ocloo (2010) reveals that medical harm is experienced as a complex process which does not end at the incident itself. Patients talked about the original Patient Safety Incidents (PSI), but also about the aftermath of harm and their feeling that doctors, healthcare providers and those responsible for regulating health professionals had also treated them poorly. Ocloo argues that these accounts present an important challenge to the dominant discourse in patient safety, which focuses on developing a ‘no-blame culture’. She does not report the age of the participants in this study but it is one of the few to present a challenge to enquiries or reviews that wish to ‘*learn messages*’.

Multi-agency public protection arrangements (MAPPA) and Multi-agency risk assessment conference (MARAC)

Related to the system of safeguards for the protection of vulnerable adults are the arrangements to monitor dangerous offenders (MAPPA) and the arrangements to monitor and prevent domestic abuse (MARAC). Local areas may include a number of cross-agency teams who meet regularly to monitor cases of individuals at risk of domestic abuse through the MARAC system. Case information may be gathered locally in a MARAC database but domestic abuse cases are more likely to be home based and so these databases, even if anonymised and available, are unlikely to be a useful source of data on abuse and neglect in care homes and hospitals. Nonetheless people who are seen as posing great risks may be

employed or volunteering in care facilities if care is not taken over recruitment and checking. A similar point arises in respect of the MAPPA databases and their supervisory systems. It is important to note of course that older people may be subject to the surveillance of such systems as potential ‘perpetrators’ of crime as well as potential victims.

Criminal cases

At the time of writing, the report of the study of financial abuse being undertaken by the Association of Chief Police Officers is imminent but other crime-related data may be promising in terms of risk reduction. The recently launched National Fraud Intelligence Bureau, for example, may provide new evidence about the vulnerability of people with early dementia who may be targeted by criminals in the community but also in care home settings (Wright 2011). Its existence points to the importance of going beyond health and social care information and to using what is collected by other government departments, such as the Home Office. Other data related to criminal justice are emerging from the reports of offences being prosecuted under the Mental Capacity Act (section 47 wilful neglect and ill-treatment). Since this part of the MCA was implemented in 2007, there have been about 300 prosecutions (Gantley, Personal communication). However, the DH does not maintain a list of these nor report which have been successful. There is the potential to investigate these prosecutions and to consider links with the decisions of professional bodies (e.g. NMC) and the ISA, as well as tracing back to see how these have been recorded in local safeguarding processes and systems. A recent report from the Lord Chancellor’s Department (early 2010, cited by Gantley 2010) suggests that there have been 200 prosecutions, meaning that it is likely that there will be growing experiences of this across a wide range of local health and social care settings, such as hospitals as well as care homes. The first known prosecution (London Borough of Newham 2009) concerning ill-treatment in a care home has been publicised, and the Evidem Mental Capacity Act study has found that this case is widely known about in adult safeguarding circles (Manthorpe et al 2009).

While not necessarily involving prosecution, there are also data relating to material in the Office of the Public Guardian (OPG) and complaints made about people holding lasting powers of attorney and court appointed deputies, as well as actual investigations and the revocation of such appointments. The OPG (2010a; DH 2010c) reports that in the past 12 months, it has responded to 883 concerns and on the basis of these concerns launched 416 full investigations. Not all the investigations resulted in referral to the Court of Protection; in some cases the level of supervision was increased or similar. Of the 54 cases which did seek changes from the Court of Protection, all but one was successful in the OPG applications to freeze the accounts, or to revoke the appointment of the deputy of power of attorney. The OPG now has a blanket policy of referring a case to the police if it believes that a criminal act has been committed, for example theft or fraud (OPG 2010b). It might be possible to look at this data to see if these reports relate to care home or community settings and to older or other adults.

In respect of anti-social behaviour, which may be part of the abuse of vulnerable adults living in care homes or related to reasons for their admission to hospital, there have been various initiatives. One promising source of data may be the newly launched pilot project from the Home Office (BBC 2011) whereby eight police forces in England and Wales have launched a project to help vulnerable victims of antisocial behaviour following lessons learned from the inquiry into the deaths of Fiona Pilkington and her daughter Francecca Hardwick. This seven-month pilot is designed to help identify and protect victims most at risk by improving response and recording systems. Any evaluation should also help establish whether care

homes are being targeted as locations. It needs to be acknowledged that definitions of anti-social behavior are contested (Bland and Reed 2000) and the overlap with elder abuse may be uncertain.

Hospital incident reporting

Moving to the NHS, interest in patient safety and high profile cases of clinical risk have led to greater commitments in developing incident reporting systems in the NHS, and in acute or hospital services in particular. Over 3 million incidents have been reported to the National Patient Safety Authority since its inception. Patient safety incidents may be defined as any unintended or unexpected incident which could have harmed or actually harmed a patient, being referred to sometimes as adverse events, adverse incidents, clinical error or near misses (Kodate and Dodds, 2008, p2). There has been a widening of this definition with the inclusion of incidents and activities that may also be classed as adult abuse (e.g. the Kerr-Haslam Enquiry, DH 2005) and the criminal activities of Shipman (Smith 2004). The term critical incident reporting is also used. In light of the various definitions, it is probably no surprise that reporting systems have frequently changed (Kodate and Dodds, 2008, p4) in a search for the most effective system. Moreover, there is strong evidence that when incident reporting systems are compared with case notes and other patient records then there is underreporting, particularly at the levels of moderately severe and minor incidents. Kodate and Dodds (2008) have investigated the literature examining the possible reasons for this (summarised as procedural, institutional, epistemological and cultural factors or barriers). They conclude that reporting rates may be strongly linked to whether those who submit such reports are confident that there will be meaningful, contextualised feedback.

Kodate and colleagues (2009) also summarise various criticisms of the investigation of the causes of such incidents, which include a lack of resources given to the process, unfamiliarity with investigation methods, being in the face of media attention, legal processes interacting with the conduct of the investigation, and an ambiguity in defining what actually are standard care practices within complex care (see also Woloshynowych et al 2005).

Within the NHS there are other sources of patient safety data contained in litigation and complaints records. In the case of Mid Staffordshire Foundation Trust, for example, where the independent inquiry (reporting February 2010) found that care had been ‘appalling’ and patients (many of them older people) had been routinely neglected, up to 1,200 more people died in the years 2005-08 than would have been expected (Francis 2010). As noted earlier, this internal inquiry is being followed by a public inquiry (commenced November 2010) investigating why the regulators appeared not to have acted sooner, again under the chairmanship of Robert Francis, QC.

The scale of patient safety incidents (PSIs) is immense and since older people are the major users of inpatient services, these issues affect them significantly:

‘It is generally agreed that about 10% of hospital admissions result in a PSI. A broader international review of nine retrospective studies of patient records on PSIs found that these made up on average 8.9% of hospital admissions within a range of estimates from 3.8 to 16.6% (NAO, 2005). Most studies suggest that deaths from PSIs are significantly under-reported. In the UK these have been estimated to fall somewhere within a range from 840 to 34 deaths a year (NAO, 2005)’ (Ocloo 2010, p510).

Our interviews with professionals suggested greater support for the benefits of a no-blame culture, but also the need to avoid the tyranny of incident counting:

‘It’s about developing a non-blame culture. It should not be a culture of “how many incidents you have got”. You don’t want to discourage people by saying “you have more than so many, or have only got so many a month”, it’s about learning and sharing learning and preventing it happening, which actions should have been taken.’ (NHS contracts monitor, 8)

As with Wood (2006) in the US we did not find data being used based on ICD codes which theoretically have the potential to provide returns on adult mistreatment and with options to note type of mistreatment or neglect and perpetrator. The reason for this may be similar to those identified in a New York State study whose authors conclude:

Physician–administrative coding of adult maltreatment using the ICD-9CM code for adult maltreatment (995.80) rarely occurs.

Incidents and Confidential Inquiries

This subject of incident reporting exposes wide variations between the data classification and data collections models used in hospitals and care homes, sometimes, it should be recalled, these are hypothetically about the same older person. The interview participants identified differences between how links are formulated between the conditions of older people in terms of, pressure ulcers, for example, and whether links are made with potential abuse and neglect:

‘My experience in the NHS is that keeping data on abuse is very sparse, and it’s categorised as many different things. So if you have an incident in the hospital or in the NHS it will often be categorised as something different to what it might be if someone else is looking at it. So the categorisation is going to depend on who it is that’s collecting the information. So, if we take the example of a pressure ulcer that’s developed in a hospital ward, a grade 3 pressure ulcer, that will be categorised as a clinical incident in the NHS and it will be recorded on the National Patient Safety Agency (NPSA) recording system as a pressure ulcer. The hospital is supposed to do a report of analysis to identify why the pressure ulcer happened but the nature of the inquiry in the NHS and the system used by the NPSA is a no blame system so, the system is the root cause analysis process, it’s about trying to find out what systems went wrong to cause something to happen.

So, although then you might get a hospital recorded as having say 5 pressure ulcers in one ward over the last 6 months, they would be looking at what systems went wrong, **they would not be calling it abuse, they wouldn’t be calling it neglect, they would be calling it systems failure.** It would be recorded by the Trust and that information would then be sent to the NPSA.

The NPSA does have a category of abuse but it’s very difficult to identify what is meant by **abuse, and it’s my experience that it’s only ever used when the NHS personnel are reporting abuse that they have noticed in others.** If they are raising an alert about a care home or about a family member they would use the NPSA category of abuse. In my **experience it’s very, very rare for that category to be used against itself against the NHS.**

If you take that example of the pressure ulcer development in the care home and a patient is admitted to hospital or a district nurse goes into a care home, it is much

more likely now, certainly in the last 18 months or so, for that to be reported as a safeguarding issue and it will then be investigated as a safeguarding issue. It should be reported by the care home to CQC but it wouldn't necessarily be reported as neglect it would be reported as a pressure ulcer. Then it would be investigated and if it's a forward thinking local authority and if it's a forward thinking District Nursing service, it will be recorded as **alleged neglect and it will be investigated as such**. That alleged neglect will either be substantiated or not substantiated or be inconclusive.' (Specialist nurse with clinical lead for safeguarding, 1) (researchers' emphasis).

This perception that hospitals have their own systems was repeated by others interviewed, both inside and outside the NHS acute sector:

'Hospital is murkier because we don't do abuse do we! The AEA Elder Abuse leaflet is around in the community but the reaction here is 'because we don't do abuse in acute hospitals we don't need it'.' (Nurse consultant, NHS Acute Trust, 2)

'It's a different culture in hospitals which is significant. 'Poor care' is the label that we use in hospital where I would say this is one of our (local authority) categories of abuse - i.e. neglect or physical abuse. It is most often about neglect in hospital but I struggle to get agreement on that from our colleagues in local hospitals. It's a real culture issue in the NHS. They are quite horrified if we say we have uncovered evidence of neglect, for example, an older person where someone is receiving inadequate care and has suffered harm that meets our definition of abuse or neglect, but we don't tend to get a very positive reaction to that from our colleagues in the NHS' (Adult safeguarding coordinator, 10).

In this way while the systems of clinical incident recording seemed comprehensive and one way of systematically assessing the nature and scale of abuse and neglect, insider knowledge suggests otherwise. A clinical specialist in nursing (1) illustrated how clinical incidents and safeguarding alerts were only recently and patchily converging:

'You will have far more pressure ulcers being caused by neglect in care homes than you have in hospitals, not because you have a difference but because of the difference of the language that's being used; the difference in the way that people see things and the difference in the way that they either consciously or unconsciously protect where they're coming from. So in the NHS you will get all the rhetoric of zero tolerance of abuse, what you actually get are conversations on zero tolerance of abuse and what does this abuse actually mean? Because a clinical incident is 'not abuse' - and there is this discourse that goes on all the time. Where someone not getting enough to eat and drink in a care home will be classified as neglect, someone not getting enough to eat or drink in the NHS is only now being started to be reported as a clinical incident. So to be actually able to look at a set of data and say we can see from this data that there's more abuse that goes on in care homes than goes on in the NHS cannot be achieved at this time because the language is so totally different and the perspectives are so totally different. When you do get actual hard data, data held by the local authorities, again the data will be skewed because people aren't reporting things as safeguarding when they occur in the NHS, as to opposed to when they occur in care homes' (1)

The Patients' Association (2009) has also drawn attention to the difficulties in determining the prevalence of pressure ulcers and quantifying NHS resources to manage them, concluding that there is a strong case for national data collection because local scrutiny is only possible if there is widespread availability of comparable data nationally. A Quality Contracts Manager employed by a Primary Care Trust (PCT) to monitor contracts with the other parts of the NHS such as Acute Hospitals identified that in monitoring hospital admissions from care homes there might be potential to have a clearer view of the state of the older person on admission and on discharge:

‘There is information around admissions to hospital from care homes that we are trying to develop. There is a drive to reduce hospital admissions from care homes to save money. This information is difficult to complete because very often the best details are not kept and tracking back to care homes from a data perspective is difficult. So we are working with the ambulance department and their information systems on response for taking people into hospital and following it through when we have patient details and what the cause was there. So if there are safety or safeguarding issues that we do pick up via that route – falls etc – we do investigate and follow that through. We have quite detailed sessions on that and it's (about) understanding. Our Trust notes every fall not only the ones that result in major harm. Grade 1 pressure ulcers are notified, because if you notify them you stop them developing.’ (Quality contracts manager, 8).

Likewise, there were mixed reports that hospital data collections systems, even if they were not picking up on clinical incidents, were being more responsive to the needs of older people to suggest a possible safeguarding referral at early stages:

‘We get quite a few (referrals) from hospitals and this has certainly increased. These are not always through care providers, some from their own homes. (We are) concerned about arrival in hospital with injuries, pressure wounds and dehydration’. (Adult safeguarding coordinator, 10)

In contrast:

‘When someone comes home to our care home from hospital with pressure ulcers, the care home can then raise a safeguarding alert about the hospital but whether they do or not depends on the local arrangements’. (Clinical nurse specialist, 1)

Post Mortem data

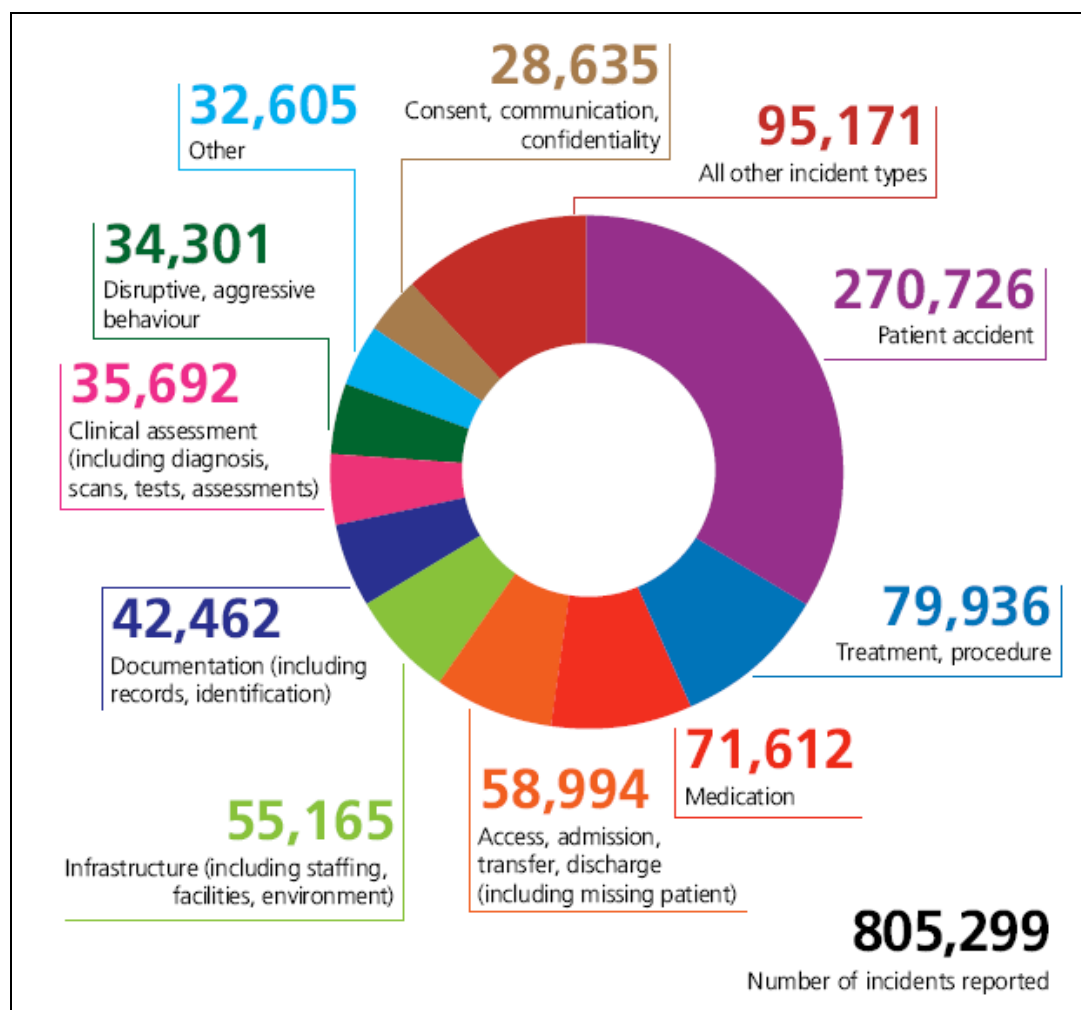
We have not been able to identify any databases concerning suspicious deaths of vulnerable adults though inquests or similar services. However, the Office of the Chief Medical Examiner, Louisville, Kentucky, in the United States (US), undertook a ten-year (1992-2001) retrospective case review of morbidity and mortality among older people aged 60 years and above (Shields et al 2004). This study investigated two categories: 1) medico-legal autopsies and 2) examinations of older people pursuant to a Clinical Forensic Medicine Program. Of the 74 post-mortem cases, 52 deaths were attributed to a homicidal act and 22 deaths were suspicious for neglect. Of the 22 living victims of elder abuse and neglect, 19 cases had been subject to physical and/or sexual assault and three individuals suffered from neglect. Such data could be investigated to consider place of current residence. Of the 15 autopsy cases

analyzed by Akaza et al (2003) in Japan, all the deceased older people had been living in the community but this model could be used more widely with permissions.

National Patient Safety Agency (NPSA)

The National Patient Safety Agency (NPSA) is part of the NHS National Reporting and Learning Service (recent announcements indicate that this will move to the DH). The NPSA receives confidential reports of patient safety incidents from healthcare staff in England and Wales. These reports are subjected to 'root cause analysis' to identify common risks to patients and opportunities to improve patient safety. Over 2.7 million reports have been received in the past five years.

Reported incident types in England, July 2007 to June 2008



The NPSA produces quarterly data summaries but these do not include information about patient age and do not therefore provide direct information on the abuse and neglect of older patients in hospital or elsewhere. The NPSA does collect information about patient age as part of the data collection process and so secondary analysis would be possible. Its National Reporting and Learning Service and other relevant materials are at:

NRLS website: www.nrls.npsa.nhs.uk/

Patient safety data (quarterly data summaries; organisational reports):
www.nrls.npsa.nhs.uk/patient-safety-data/

Patient safety incident reporting portal (includes tab linking to information on Patient Safety Direct and how to improve reporting):
www.nrls.npsa.nhs.uk/report-a-patient-safety-incident/

Seven Steps to Patient Safety in General Practice (this site includes a series of web seminars that were hosted/ran on each step -
www.nrls.npsa.nhs.uk/resources/?EntryId45=61598

The definitions of harm employed by the NPSA are listed in the original ‘Seven Steps’ (NPSA 2004), with Appendix 4D (p111), giving as an example the dataset category of ‘Patient abuse (by staff/third party)’ with the accompanying subsets of ‘physical or verbal’. About the system in general, one NPSA participant observed:

‘We publish our guidelines and have our definition of patients’ safety. We also have our definitions of levels of harm degrees of harm ranging from no harm through to death as a direct consequence of patients safety incidents. I think the challenge around safeguarding is how narrow or wide do we define safety? Because something could be a safety incident but may or may not be safeguarding and *vice versa*.’

Q ‘And how are they distinguished?’

A ‘We obviously have our own definitions but there are a list of multiple systems of health and social care both locally and nationally as to what constitutes safety or constitutes safeguarding etc’. (NPSA, 7)

This means that the NPSA threshold may be much lower than that operating elsewhere. One participant from the NPSA argued that this was useful and effective:

‘In terms of how we define harm it can be anything from low harm where the impact was prevented because somebody realised that something was going wrong and somebody did something about it - to no harm because it deviated from the expected pattern of care - nothing actually happened to the patient; through to death as the direct consequence of a patient safety incident. Within that, anything from low harm, moderate harm, severe, so anything in between and within that. We do get reports of abuse, neglect or however you want to define it, but they are in the context of patient safety incidents so someone has to get into their mind that this is a patient safety incident and that’s part of the issue as well to make the connection between safeguarding and safety and harm. We need to know what happened, but why did it happen, so that it doesn’t happen again in the future’ (NPSA 7).

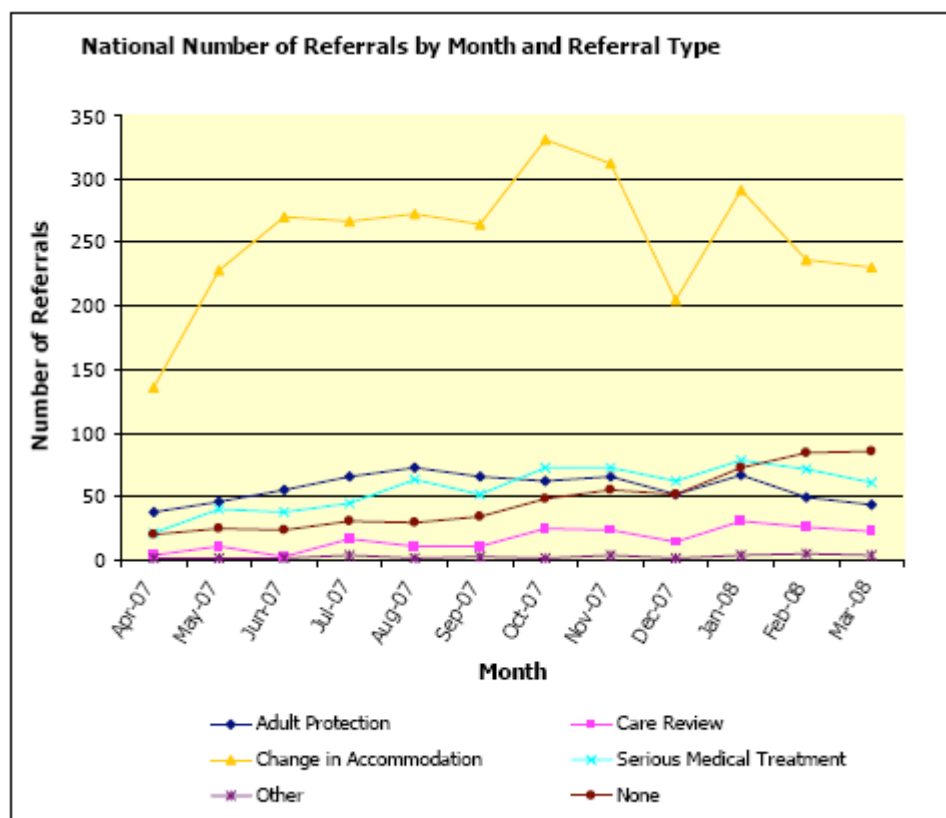
Patients Advice and Liaison Service (PALS)

Patient Advice and Liaison Services are organised by NHS Trusts and Primary Care Trusts to provide patients with an identifiable person to whom they can turn if they have a problem or need for information or advice. PALS are intended to link with vulnerable and 'hard to reach' groups, and act as a catalyst for change and improvement in the Trust.

The way in which PALS services are organised and the level of commitment varies widely between Trusts. PALS services do not consistently collect data about service users/patients which would lend itself to secondary analysis to identify cases of neglect and abuse of older patients. Links with the newly proposed Local HealthWatch (LHW) systems remain to be articulated.

Independent Mental Capacity Advocacy (IMCA) Service

The Mental Capacity Act 2005 created the Independent Mental Capacity Advocacy (IMCA) role as a safeguard for people without the capacity to make certain important decisions and who have no-one (relatives and friends) to support them. It includes provision for IMCAs to act for people where there are allegations of abuse and those close to the person are implicated (see Redley et al 2008). The Act introduced a legal duty on NHS and social care staff to refer eligible people to the IMCA service. The IMCA service started on 1st April 2007 and produced its first annual report in June 2008.



Source: IMCA service Annual Report, June 2008 p24

In the case of Adult Protection or safeguarding allegations, an IMCA can be called on to help either or both a possible abuser and an allegedly abused person lacking decision making capacity. In 2007-08, 681 people received an IMCA service in respect of adult protection cases. This provision has been widely welcomed by adult safeguarding coordinators (Manthorpe et al 2009) and other stakeholders (Banks and Redley 2009) but not consistently by hospital clinicians (Luke, Redley, Holland & Clare 2008).

Demographics of IMCA referrals April 2007- March 2008

		Adult Protection	Care Review	Change in Accomm.	Other	Serious Medical Treatment	Unknown	Total	%
Gender	Male	274	89	1430	11	336	259	2399	46.3
	Female	407	101	1613	17	339	294	2771	53.5
	Unknown		1	4			4	9	0.2
	Total	681	191	3047	28	675	557	5179	100.0
Age	16 - 17	2		12			1	15	0.3
	18 - 30	82	11	93	2	37	31	256	4.9
	31 - 45	81	14	239	2	97	55	488	9.4
	46 - 65	138	43	683	5	226	142	1237	23.9
	66 - 79	130	45	797	9	149	127	1257	24.3
	80 and over	230	74	1141	10	142	140	1737	33.5
	Not known	18	4	82		24	61	189	3.6
	Total	681	191	3047	28	675	557	5179	100.0
Ethnic Background	Not Specified	15	4	57		8	30	114	2.2
	White British	570	163	2518	26	563	434	4274	82.5
	White Irish	15	2	88		11	7	123	2.4
	White Other	16	9	117	1	20	18	181	3.5
	White + Black Caribbean	1		10		4	3	18	0.3
	White + Black African		1	8		2		11	0.2
	White + Asian	2		5		1	2	10	0.2
	Mixed White Other			4		1		5	0.1
	Asian British or Indian	7	3	15		3	4	32	0.6
	Asian British or Pakistani	10	3	15		1	6	35	0.7
	Asian British or Bangladeshi	4		8		1	3	16	0.3
	Other Asian	8		12		5		25	0.5
	Black British / Caribbean	4	1	63		18	11	97	1.9
	Black British / African	4		23	1	6	6	40	0.8
	Other Black	2		6		3		11	0.2
	Chinese	2	1	3		5		11	0.2
	Other Ethnic Category	3	1	19		6	4	33	0.6
	Not Established	18	3	76		17	29	143	2.8
	Total	681	191	3047	28	675	557	5179	100.0
Nature of Client's Impairment	Acquired Brain Damage	45	9	150	1	27	21	253	4.9
	Autism Spectrum Condition	24	10	64	1	13	13	125	2.4
	Cognitive Impairment	45	16	229	1	27	37	355	6.9
	Combination	28	9	161	5	40	27	270	5.2
	Dementia	268	77	1272	10	129	163	1919	37.1
	Learning Disability	150	38	532	5	221	139	1085	20.9
	Mental Health Problems	72	19	385	4	104	74	658	12.7
	Not Specified	4	1	52		6	45	108	2.1
	Other	22	9	114		23	22	190	3.7
	Serious Physical Illness	23	3	87		64	14	191	3.7
	Unconsciousness			1	1	21	2	25	0.5
	Total	681	191	3047	28	675	557	5179	100.0
Place of residence at the time of referral	Not Specified			3		3	1	7	0.1
	Own Home	197	15	261	9	59	15	556	10.7
	Care Home	265	119	926	7	217	42	1576	30.4
	Hospital	126	38	1466	9	320	57	2016	38.9
	Supported L	35	7	162		39	10	253	4.9
	Uncertain	1		10		1		12	0.2
	Prison	1				3		4	0.1
	Other	29	5	148	1	14	12	209	4.0
	N/A	27	7	71	2	19	420	546	10.5
	Total	681	191	3047	28	675	557	5179	100.0

Source: Independent Mental Capacity Advocacy Service Annual report, June 2008 p23

IMCA referrals for Adult Protection may be an indicator of levels of abuse, neglect and mistreatment among people who lack capacity in care homes and hospitals and the database from which the annual report statistics are drawn may lend itself to secondary analysis.

Redley and colleagues' (2008) investigation of IMCA involvement in Adult Protection procedures included: 1) An audit of all Adult Protection cases referred to 10 organisations providing IMCA services in England; and 2) Qualitative interviews with a sample of Advocates, IMCA managers, social workers and Adult Protection Coordinators. Of the 204 referrals made to the 10 IMCA provider organisations in the study period, 63 per cent of cases involved women and more than half the cases involved people over the age of 65. All participants reported that involving an IMCA in Adult Protection procedures was beneficial to alleged victims or alleged perpetrators lacking capacity. In their view the number of Adult Protection referrals to IMCA services had been fewer than might be expected. However, the types of disabilities affecting decision-making capacity, and the relationships between people and the alleged perpetrators, were consistent with expectations.

This area illustrates the evolution of concepts of abuse which are being perceived and categorised in new areas and disputed, as in this case example:

‘What’s beginning to happen is that patients who lack capacity, where clinicians have decided on a particular course of treatment if they have not consulted with the IMCA (Independent Mental Capacity Advocate) if we are making decisions on our own and particularly withdrawal of treatment with patients we have decided are at end of life - (there is) distress on all sides.

Last week we had a situation. We looked at what evidence there was and what clinical decisions were appropriate. Then the IMCA came in and the way she presented her case we thought very subjective - as if we had apparently made our decision because the patient was 90 and had a learning disability. The geriatrician was very upset. “I don’t care how old or whether she has a learning disability or not, I am looking at septicæmic shock, dehydration, malnutrition and discharge from another hospital ‘not for end of life care’ and no discussion – she is dying. She’s allowed to die”. Now that issue is being conveyed to the safeguarding lead as a safeguarding issue. No! We have very good relationships with the safeguarding lead and we’re saying you need to look at all the information. I am not happy about this. There is more of that as we are being readily challenged and we are consulting with care and treatment for people who lack capacity. There’s a lot about how we are being challenged and how non-medical staff are perceiving what we are doing – as if we are trying to finish people off.’ (Nurse consultant, 2).

Deprivation of Liberty Safeguards (DoLS)

In response to a judgement in the Court of Human Rights, concerning Article 5 of the Human Rights Act, the government amended the MCA 2005 by adding the Deprivation of Liberty Safeguards (DoLS). The safeguards apply to hospital in-patients or registered care home residents (possibly those in supported living accommodation as well) who are defined as having a mental disorder and who:

‘for their own safety and in their own best interests need to be accommodated under care and treatment regimes that may have the effect of depriving them of their liberty but who lack the capacity to consent’ (Foreword, Ministry of Justice, 2008).

There is little data yet about the use of DoLS and so it is not possible to see if they are providing substantial evidence about unlawful restraint or deprivation of liberty although a

study of older hospitalized psychiatric patients conducted prior to the implementation of DoLS found that three-quarters of the participants that lacked capacity to consent to admission were not formally detained (and the study excluded people who were very unwell) (Moxon et al 2009).

. In their first nine months of operation about four per cent of all applications were not authorised (n=125) (Department of Health 2010a). However, the DH has expressed its concerns about the level of DoLS applications and authorisations in the first year (April 2009 to March 2010) which stood at about a third of those it had estimated. The DH attributed this to significant and unacceptable variations in activity in different parts of England. A recently commissioned study of DoLS (Langan et al 2010) may provide greater information about these variations in practice.

While not always related to the strict criteria of DoLS, restraint was highlighted in several interviews as being problematic in practise and in recording:

‘We have a restraint policy which we’ve just finished writing. Lots about the Mental Capacity Act and what is appropriate or is not and assessment. When you can legally and professionally hold or restrain a patient. Overarching policy based on the MCA and Human Rights Act and then guidance for staff. Clinical holding is physical restraint. If you have to do it more often that’s clinical holding. National Patient Safety Agency do surveys asking ‘do you have a policy?’ Responses were that some acute trusts said ‘yes’. We are trying to be careful. Others said ‘no’ we just don’t do it. But they are doing it all the time – in ITU, detox, post-operative brain injury, delirium and delivering medication to stop delirium so we are doing it all the time, doing it properly, being reviewed - emergency department and out of hours you telephone social services and safeguarding team. On the wards there is a different pathway and the things that constitute abuse are physical injuries, neglect, malnutrition, undignified attitudes...’ (Nurse consultant Acute Trust, 2).

Not all participants reported that systems were clear in hospital settings, confirming the DH data about partial implementation of the DoLS initiative. Evidently, work on this subject was being planned at the NPSA at the time of the interviews (mid 2010):

‘Incidents involving people in hospital beds would go to, for example, anaesthetic leads at NPSA. I was at a conference yesterday and two practitioners were speaking about elderly care in hospital. It seems there is a big problem when someone with an Alzheimer’s dementia is admitted to a general hospital and some of the things have been staff training and it’s not always helped in dealing with some who’s elderly and if it’s expected that some harm can be caused. There are issues of restraint. I have not looked at that data and we should look at this. When someone is restrained it should be reported as a patient safety incident. (Colleagues) are to take forward a piece of work around control and restraint. Currently (we are) updating data with information about training, de-escalation, training for handling situations before using restraint.’ (NPSA representative, 6).

Reporting abuse and neglect

This final section relates to most of the data sources described in this report, although more specifically in terms of reporting individual incidents. As portrayed in a number of data

sources and interviews, there is a range of means and channels through which abuse is identified and a strong theme in virtually all of the interviews was that there is a great deal of information which potentially relates to abuse of older people in institutional settings but it is not necessarily labelled as potential abuse or neglect. Participants reported that the decisions made by individuals at the point at which they identify a potential problem are critical in terms of:

- whether they identify it as a potential problem or not
- whether they feel comfortable to challenge a situation
- how they categorise the situation in their own minds (e.g. as a clinical issue, patient safety issue, safeguarding issue, systems issue)

and consequently:

- how they report the issue
- how the issue, and the data describing it, come into the system.

This was illustrated in comments from a spokesperson from the NPSA:

‘How they (managers and practitioners) define it at that point when they recognise that something isn’t right and say, for example, that someone has a pressure ulcer. It’s whether they see it as a clinical incident or a patient safety incident or a safeguarding issue - and that’s a human system ... A lot of it is dependent upon the person themselves, completing a report and deciding “this is something that I feel sufficiently strongly about and I think it’s worth reporting” and also something that they are comfortable reporting. It’s fair to say that most people are comfortable reporting things when they themselves haven’t made an error, but they are less comfortable reporting things when they have’. (NPSA, 6).

Again the example was given about the willingness of staff in an Acute Hospital to flag up possible abuse - if responsibility for it was not at their door:

‘If a patient is admitted to us (in a hospital) and staff have concerns about their care and welfare prior to admission it gets immediately notified to Safeguarding Adults lead in the hospital and then the Safeguarding Adults Team will have a look and initiate initial investigations. That all depends on someone flagging the concern. It could be relative or carer or, quite often, clinical staff who are concerned with the care and treatment that the person has been less than optimal. Pressure sores go straight to the top – tissue viability and nutrition. The Safeguarding Team hold that data on that and also on the numbers of people who we had initiated a safeguarding request about’ (Nurse consultant, 2).

As another participant commented, on the basis of experience of many alerts, ‘This all comes down to what people feel comfortable reporting’ (NPSA, 7).

There was a sense in the interviews that there are likely to be data that do not find their way into systems which could identify abuse. This could be in the form of things that have happened but not been reported, for example, another participant from the NPSA, admitted:

‘We don’t necessarily see it but that doesn’t mean it has not happened. There is a fear that if you put a label of abuse on it, does this stop people reporting? If staff know they report a sexual safety incident and it would then be loaded up into the abuse field and Trusts maybe get twitched that the CQC may come down hard on them ...?. Is this normal, what could have been done to prevent this, could it have been prevented – sometimes not. My concern is that when an incident happens it’s about what happened but if we don’t get this reported to us? And I understand that staff are busy ... but I want to know whether the safeguarding lead in the Trust was informed of that because it shows they have clear protocols and staff know what to do when that happens, and when I go back to the Trust they can show that it has been investigated and this was the outcome’ (NPSA, 6).

Or there could be concerns which are either not raised, or are raised but not identified as a potential abuse issue, so no action is taken. One experienced adult safeguarding professional based at the DH commented:

‘It’s not only what goes through an incident, it’s what goes through in the general provision of care which might deliver people something useful. Most authorities will have some way of gathering information about people’s concerns, but they might be low level stuff and might not be picked up at the time. People often don’t know what to call it...It’s about persuading people it’s worth making a report. Not just professionals but family members and other visitors, e.g. professional visitors to care homes – GPs, social workers, and for members of staff to raise concerns – and then where that goes – some to the regulators, some to social services – different avenues’ (Adult safeguarding expert, DH, 4).

In this context it is chilling to read the report of the inquiry into the long history of poor care of patients, mainly older people, at Mid Staffordshire Hospital (Francis 2010). The report emphasised that patients, mostly older people, were the people who had borne the brunt of the failings of this hospital where staff were not supported to be open and learn from mistakes, where many staff at all levels did not focus on quality care, where organisational and individual ambitions were a priority, and where systems failed to share information on risk and to work collaboratively. Information from whistleblowers made little impact (a source of general data that has been rarely scrutinised collectively, see Erlich 2006). In this situation, data were not used to ameliorate the situation or to limit the spread of poor practice, but in the inquiry data provided useful contextual background to harrowing personal or family accounts. One challenge for those with responsibilities in data analysis and collecting is to see that these lead to better outcomes. All complaints made in one year by older patients in an Australian hospital (Anderson, Allan and Finucane, 2000) were investigated – with a finding that about three-quarters had been made on their behalf by others, but in the UK it is commented that surprisingly little use is made of complaints arising in hospital settings (Haw, Collyer and Sugarman 2010).

Finally, use of existing information sources to investigate the nature and extent of problems of ‘abuse’ of care-workers and other staff and residents by other residents/patients, or by visitors to care homes and hospitals highlights the complexity of care home environments.

While such staff are not ‘vulnerable adults’, there may be scope to investigate the links between staff and resident experiences and the culture of an organization. There is continued evidence that work in care homes can be dangerous. Menckel and Viitasara (2002) conducted a nationwide survey of the prevalence of violence and risk situations in Sweden. The survey was sent to a stratified sample of 2800 local government employees in the care and welfare sector (response rate 85%) working mainly with older people or people with developmental impairments (learning disabilities). Half the respondents (51%) had been affected by threats/violence, either verbally or physically, over the previous year, with over nine percent experiencing acts of violence or threats on a daily basis, and 67 percent several times a month. Those most at risk appeared to be assistant nurses and direct carers (care workers). Verbal threats were commonly reported (79%), but 66 percent reported physical assaults. A recent US study reveals the impact of such violence by demonstrating the high risk of musculoskeletal pain among nursing home staff (Miranda et al 2011). Almost half (48%) of the 920 respondents in this study said that they had been assaulted at least once during the preceding three months by a resident or a resident’s visitor, while one in four had received several violent attacks. Scott et al (2010) note that care home staff’s experience of violence by residents with dementia may be unreported in the main with cultural pressures not to report and acceptance of the risks as part of the job.

In the UK, there are reported to be huge regional variations in the number of violent and abusive incidents against social care staff recorded by councils (Community Care 2010) and such disparities in reports of violent incidents has led to call for a national record system from social care unions although Local Government Employers are reported to have rejected the development of a national violent incident register and data collection similar to the NHS (Lombard 2010). As noted above, the NHS Staff Survey seeks reports of bullying and violence and while this may be under-reported it is a reliable source of data that might be analysed in the context of elder abuse to explore organisational cultures and possible links between risks to staff and risks to patients or residents. The NHS’s commitment to health and wellbeing among staff is consistently reported and linked to quality of care for patients (Boorman 2009). There is an argument that recording data related to violence and injury at work for one set of staff – in the NHS – but not in other CQC regulated settings may be inequitable.

This leads more pertinently to the risks to older people living in care homes of exposure to violence and harm from other residents. Terming this ‘resident-to-resident aggression’ (RRA), Rosen et al (2008a) held 15 focus groups with 96 staff of a large urban US nursing home, and one focus group including seven residents who were not cognitively impaired. Participants listed 35 types of RRA, 29 triggers of such behaviour and 25 strategies staff members used to prevent or cope with aggression among residents. Rosen et al (2008a) conclude ‘*RRA is a ubiquitous phenomenon in nursing home settings*’ Following this, in a pilot study Rosen et al (2008b) report that 2.4 percent of residents reported personally experiencing physical aggression from another resident and 7.3 percent reported experiencing verbal aggression over a two-week period. Most respondents rated the events as moderately or extremely disruptive. In their second pilot study, 12 nurse-observers identified 30 episodes of RRA over one single 8-hour shift, 17 of which were physical (Rosen et al 2008b). Continuing their work, Rosen et al (2010) cite evidence suggesting that most sexual aggression against older adults occurs in long-term care facilities (care homes). They note that fellow residents are the most common ‘perpetrators’, attributing this to hypersexual behaviour related to dementia. Data related to such risks might be the subject of Serious Incidents reports in care home settings, or similar, and merit further investigation.

6. Conclusions

At the time of writing this report, there was no good single national level data source available, suitable for secondary analysis, covering the abuse, neglect and mistreatment of vulnerable older people in care homes and hospitals in England although IMCA and ISA data might be candidates for consideration in relation to small select groups of older people at risk or where allegations have been made. As with all data sets there are many issues in statistical quality (ONS 2007c): notably relevance, accuracy, timeliness, accessibility and clarity, comparability and coherence. We conclude that variable definitions make many comparisons risky since like will not often be compared with like.

Individual local Adult Safeguarding Boards produce annual reports which may allow local trends in the abuse and neglect of vulnerable adults to be identified, however, the quality of this data and their consistency are variable. Local authority held data is currently being collected by the NHS National Information Centre for Health and Social Care (AVA) and the first 6 month tranche of data will be published in 2011. This data collection exercise was designed to be repeated for a whole year from April 2010 to March 2011, and data provision by individual councils with adult social service responsibilities was designed to be mandatory, so there has been greater confidence that perennial difficulties of data reporting on the abuse, neglect and mistreatment of vulnerable older people in care home and hospitals in England might be eased. The AVA looked set to be suitable for secondary analysis and longitudinal studies. This was welcomed by informants in this study as a huge resource for the sector. However, interviews took place before the announcement that this data collection will be in jeopardy. We suspect that this news may cause members of adult safeguarding communities some concern.

At the other extreme are the personal case studies found in the individual 'Fitness to Practise' hearing reports produced by the professional regulatory bodies and those reported by campaigning organisations, but, except in the case of the Nursing and Midwifery Council, these do not provide a good potential source of quantitative data for secondary statistical analysis. Their role in aspects of adult safeguarding, as with public inquiries and serious case reviews, attracts media, public and political attention and could merit greater narrative analysis but it is hard to draw comparisons.

The Care Quality Commission (CQC) and the Independent Safeguarding Authority (ISA) are both still in their infancy and while neither at present is a potential source of data on the specific abuse, neglect and mistreatment of vulnerable older people in care homes and hospitals in England, this may change as the organisations develop and their databases become more comprehensive. The scrutiny of the POVA database provides an indication of the great potential for secondary data analysis.

Applicable to only small numbers of older people, the Independent Mental Capacity Advocacy remit includes Adult Protection as one of its criteria for advocacy and also records the location of the advocacy partner, including care homes and hospitals, and the age or age group, ethnicity and gender of the client. The database from which the IMCA service annual reports are drawn would lend itself to secondary analysis which might shed light on the possible risks facing some highly vulnerable older people (by definition lacking decision making capacity) taking place in care homes and hospitals. It is likely that the offences under the Mental Capacity Act 2005 of wilful neglect and ill-treatment will merit analysis as the

number of prosecutions grows in number. There is an opportunity for the Department of Health to monitor the use of this Act in this regard.

Our findings therefore resonate with an investigation of data sources in the US undertaken by Wood (2006). This report observes that databases that might yield information on elder abuse fall into two categories:

- 1) Data that are regularly coded for either claims or regulatory purposes—in hospitals and in care homes
- 2) Data collected continually, episodically, or periodically (often annually) for research, evaluation, and policy making purposes (Wood 2006, 57-58).

However, even with some of the greater resources available to US analysts, Wood concludes that elder abuse data remain ‘extremely difficult to identify, and generally fall below the radar screen’ for four main reasons:

1. ‘Providers and professionals coding the information lack the training to recognize a fact pattern or medical condition as involving elder abuse. There is no paradigm or “frame” that makes elder abuse indicators evident’;
2. ‘Elder abuse often is secondary to other conditions or case types that are more likely to be coded’;
3. ‘There are no incentives for coding or reporting information on elder abuse, and there may be conflicts or disincentives’; and
4. The largest single driver of data on which elder abuse information might be based is adult maltreatment codes (ICD) which are exceedingly used.

In the US context she recommends 11 different approaches to data collection (design of surveys, use of agreed definitions and classifications) and analysis (potential for correlation) In the context of the UK such recommendations might be worth exploring through the establishment of a Data User Group that would have a brief to make recommendations to those responsible for the data collection identified in this study.

This study has highlighted several areas for further exploration. These include further research on the potential of a single data set such as the AVA (should it survive or the alternatives of localism), the impact of data collection and monitoring on cross ministerial policy making and on practice development, on the capacity for person-centred care to fit with the burdens of data collection, ageism in policy-making and services, and narrative research and thematic analysis relating to care recipient, patient, practitioner and managerial experiences.

In summary, the following messages arise from this study.

Policy makers: the impact of the changes proposed to the AVA system is giving rise to concern – an Equalities Impact Assessment might be one route to investigating this. There is scope for national collation of prosecutions under the Mental Capacity Act 2005, of the activities and outcomes related to the IMCA service, and related legislation, and for continued exploration of the value of serious case reviews. Monitoring of the proposed changes to the ISA remains relevant. There is scope to make use of data sources that are being collected by other government departments, such as the Home Office, some of which

include people living in care homes for example, the data collected by the National Fraud Intelligence Bureau and coroners. We recommend the establishment of a Data User Group to take forward some of points made in this study and to make the most of the opportunities of all the many forms of data that are being produced currently and to reduce the risks that they cause disproportionate burdens for those collecting the data and are not used to their full potential. It is in the hands of policy makers, across government departments, to help clarify the endemic problems of confusion of terminology and definitions in this area. Policy makers are also best placed to consider the cost-effectiveness of data collection methods and system maintenance.

Regulators and professional bodies: analysis of material relating to professional fitness to practice investigations and findings might usefully consider age and location of offences or poor practice – the regulators may wish to consider a common data collection framework. It would be helpful to relate this to the ISA new format. The CQC has a very powerful position as a new regulator and should ensure that its data command the support of other stakeholders and are widely useful.

Adult safeguarding boards: if the AVA system is not nationally mandated then local boards may wish to consider a minimum data set for their areas. A common framework for this would facilitate analysis and comparison and potentially be value for money. Organisational restructuring in primary care will necessitate attention to sustaining data exchange and analysis at local level. Publication of the summaries of serious case reviews might be helpful to distill key messages and to command public confidence that safeguarding activity justifies resources. Local links with the Department of Work and Pensions and Police services who may be able to offer local intelligence and to transmit national material may broaden their scope to collect local data, particularly relevant to financial abuse.

Commissioners: in considering reports of Serious Untoward Incidents or similar ‘events’ these may be referred to local safeguarding services; commissioners should have in place a system to ensure that this is carried out and be aware of providers’ different definitions of Serious Incidents and other related terms. We found inconsistency in their usage and of practice around safeguarding and clinical governance. The demise of PCTs and SHAs leaves certain functions to be reallocated or removed; these changes merit partnership involvement.

Research and information communities: should offer greater clarity of terminology and should archive data sets. Data concerning hospital events such as Serious Untoward Incidents and incidents in care homes may be worth further investigation. Coroner data remains to be investigated from the perspective of adult safeguarding. Research that fails to collect information on age and location should justify such omissions.

Older people’s groups: may offer assistance and support to individuals and families in pursuing matters, in supporting campaigning organisations and in promoting a culture of service quality rather than unwarranted blame. Their role in exposing issues in hospital settings is being newly mirrored by addressing problems in care homes locations. Carers’ groups are also identified as important in revealing concerns and in trying to improve quality of care. Many staff are highly supportive of such activities and are sensitive to ‘resident on resident’ abuse about which we know so very little in the UK.

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